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UNIVERSITY OF SAN DIEGO
Hahn School of Nursing and Health Science
DOCTOR OF PHILOSOPHY IN NURSING

ACCESS TO CARE: THE EXPERIENCE OF COMMUNITY-DWELLING OLDER
ADULTS RECEIVING MEDICARE AND MEDICAID

by

Mary Ann Simanello, MSN, RN

A dissertation presented to the
FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE
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In partial fulfillment of the
requirements for the degree
DOCTOR OF PHILOSOPHY IN NURSING

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ABSTRACT

Access to care represents a leading health indicator for meeting the complex healthcare and social needs of an exploding population of older adults living in the United States. This qualitative study was undertaken to discover the *essence* of access to care by community-dwelling older adults with Medicare and Medicaid. Participants were recruited from a metropolitan area in Southern California. Thirteen women and men aged 65 to 91 described their experiences with accessing care during a face-to-face, audio-recorded interview. The study aimed to: describe experiences of access to care, identify facilitators and barriers to care, and describe the effects of facilitators and barriers to care with regard to the participants' perceptions of health.

Situated in a Husserlian phenomenological approach, in-depth descriptions lead to discovering the concepts that gave common meaning and understanding to the phenomenon, access to care. Five major theme categories illuminated the essential structure: navigating the system; negotiating the system; "it was just too difficult"; "it costs money to be ill"; and "I'm just thankful for everything."

The themes depicted the *human experience* as evidenced by *real, lived* situations. Eleven sub-themes further illustrated the various perspectives and unique understandings of accessing healthcare. The themes developed add to the paucity of available information about older adults with similar demographic characteristics. They reflect and support some of the barriers described in the literature that can limit access to healthcare, those being financial, structural, and personal barriers.

The findings generate important insight into understanding *what* it is like to get healthcare services as an older adult receiving government-subsidized health insurance. Limited economic resources and their relationship to decision-making for healthcare spending are a critical area for future research. Examination of the decision-making process for healthcare used by older adults with no family or significant other is indicated. A stronger focus is needed towards investigating access to medications, health information, transportation, safe housing, and nutritious food and their relationship to increasing quality and years of healthy life. Nurses and other health professionals identified as people who make the system work deserve further exploration in their role as facilitators to accessing care.

DEDICATION

This dissertation is dedicated to my parents, James Vincent and Dolores Catherine Simanello. Their steady and generous support throughout my seemingly endless years of educational pursuit allowed me to reach the top of my Mt. Everest.

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Many special people supported my efforts in pursuing doctoral studies and in completing this dissertation. To my son, Joseph, and my daughter, Adrienne, “Thank you.” You have been my inspiration for continuing my academic dream. Your patience and understanding of my commitment to this goal will always be in my heart. I also want to thank my very extraordinary family for their endless faith and support; they have always been there for me.

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Chapter I

Focus of the Inquiry

Those who manage to get Medicaid have struggled to find decent doctors. Medicaid pays physicians well below the rates of commercial insurers, and doctors perceive the poor as “difficult” patients, sometimes with reason. Poor patients’ ailments are made worse by delays in getting care, and they show up at doctors’ offices with more of what one physician called “sociomas,” social problems that range from not having a ride to the doctor’s office, to drug addiction, to homelessness, to the despair that accompanies miserable life circumstances (Abraham, 1993, p. 4).

Phenomenon of Interest

Eliminating health disparities is one of the overarching goals of Healthy People 2010 (USHHS, 2001a). A leading indicator contained in this goal is promoting equal access to culturally competent, comprehensive, community-based healthcare for every person in the United States. Health insurance, a higher income, and a regular source of primary care are strong predictors of access to quality healthcare. However, barriers such as not having enough health insurance to cover necessary services, the lack of

primary care providers, or cultural differences, can inhibit access to needed care and services (USHHS, 2001a).

Access implies that a person or people have the available resources, such as adequate insurance coverage, a primary care provider (PCP), and facilities in close proximity to obtain care (Aday, 2001). Frequent interactions with healthcare providers do not necessarily guarantee equity in the care given and satisfaction with the care received. Indifference to the less advantaged and discriminatory health practices compounds the susceptibility to risk factors that vulnerable populations face. Language barriers, cultural diversities, and lower education are a few of the factors that can restrict a person's ability to be actively involved in caring for their own health.

System barriers such as Medicare payment cuts to physicians, nurses, and other health professionals also impede access to care for America's seniors (ManagedHealthcare.Info, 2002). Other restrictive factors may include the inability to seek preventive screening and treatment, to understand medical advice, to comply with instructions, and to read health education materials. Additional obstacles may be lack of transportation or appropriate transportation services, functional limitations in carrying out activities of daily living (ADL) or discriminatory practices towards marginalized groups such as the poor, the elderly, and the disabled.

Access challenges suggest that inadequate or poor quality of care is more likely to adversely affect health outcomes than is biology or genetic characteristics (Andrulis, 2000). Researchers have not yet determined why people of a particular ethnicity, race, or income experience more difficulty in accessing care or experience a

lower quality of care. But, research done to date reports that disparities do exist and continue to exist among these particular groups. Direct dialogue with older adults who receive Medicare and Medicaid can be a method of inquiry for identifying other sources or barriers to care not commonly known to exist.

Medicare and Medicaid

The Medicare and Medicaid programs were established under the Social Security Act of 1965. Within the Department of Health and Human Services (DHHS), the Centers for Medicare and Medicaid Services (CMS) have the responsibility for administering both programs. Medicare is the national health insurance program for people aged 65 years and older; for some people under age 65 with disabilities; and for people with End-Stage Renal Disease (ESRD). The Medicare program traditionally consisted of two parts: Hospital Insurance (HI) known as Part A and Supplementary Medical Insurance (SMI) known as Part B. The Balanced Budget Act (BBA) of 1997 established a third part, the Medicare Advantage program. Known as Part C, Medicare Advantage provides beneficiaries' the option to participate in private sector healthcare plans (CMS, 2005a).

Medicaid is a jointly funded cooperative program between the Federal and State governments to assist states in providing adequate medical and health-related services to eligible needy persons. Within the broad guidelines established by the Federal government, each state has the authority to administer its own program and set its own eligibility, scope of services, and rate of payment guidelines. Medicare beneficiaries with low income and limited resources may also receive additional health benefits such as prescription drugs, durable medical equipment, eyeglasses, and

hearing aids through their State Medicaid program. For some low-income older adults, Medicaid provides a safety net as a supplement to Medicare by covering the cost of the premium, co-payments, deductibles, and some other health services not covered by the Medicare program (CMS, 2005b).

In California, the MediCal program is the State Medicaid program. The program provides MediCal to the aged (65 years or older) or disabled with no share of cost if countable monthly income is at or below \$1,028 for an individual or \$1,437 for a married couple (if both apply). Approximately 140,000 low-income aged or disabled persons qualify for MediCal with no share of cost (Health Consumer Alliance, 2005). The *2005 Poverty Level Guidelines* puts an individual with an annual income of \$9,570 or a monthly income of \$797.50 at the 100% poverty level. An aged or disabled person living in California would likely have a monthly income below the 133% poverty level (\$1,060.68 per month) to qualify for MediCal with no share of cost (CMS, 2005c).

A survey of MediCal beneficiaries in California reported that 56% of the people had difficulty finding a doctor in close proximity that accepted MediCal (California HealthCare Foundation, 2003). Physician participation in the Medicaid program is voluntary. But ample numbers of physician participation are critical for ensuring that beneficiaries have access to needed health services in a timely manner. California's Medicaid program is the largest state program in the United States but has one of the lowest reported rates of participating physicians (Bindman, Yoon, & Grumbach, 2003).

Although one in six Californians are covered by MediCal, 45% of the physicians practicing in California are unwilling to treat MediCal beneficiaries. For every 100,000 people in California there are 56 primary care providers (PCPs). But because many PCPs limit the number of MediCal patients they will see, there are only 38 PCPs for every 100,000 people covered under MediCal (California HealthCare Foundation, 2003). This number represents one-third less PCPs than the 70 available to those in the general population and below the 60 to 80 PCPs per 100,000 recommended by the Department of Health and Human Services, Health Resources and Services Administration. Reasons cited for the lack of participation in the State Medicaid program are low reimbursement rates, shortage of specialists, and less compliant, more difficult patients (Benko, 2003).

Approximately 42 million persons nationally were enrolled in one or both of Parts A and B of the Medicare program in 2004. About 5 million participate in a Medicare Advantage plan (CMS, 2005a). California had a Medicare enrollment of nearly 4 million in 2002 (CMS, 2004d). California projects Medicaid beneficiaries will increase to 6.8 million for 2005-06. This is an increase of 1.8 million since 1998-99. The Governor's Budget proposed a General Fund increase of 8.2% above the revised 2004-05 Budget Act for the MediCal program. However, reforms are being proposed that will reduce the escalating, unsustainable costs that the program incurs (California Department of Finance, 2005a, 2005b).

Given the external forces that impact access to care for those with government subsidized health insurance, it is prudent for researchers to explore the phenomenon of access to care from the perspective of those who have lived experience. The healthcare

literature has repeatedly shown the compelling relationship between income disparity and health status and the tendency toward poorer health and poorer health outcomes for those of low socioeconomic status (SES) (Bruder, 2002; Flaskerud & Winslow, 1998). The number of older people living in poverty rose from 3.4 million in 2001 to 3.6 million in 2002 (Proctor & Dalaker, 2003). Should this trend continue, the equity in care will remain an economic, social, and healthcare issue unless more aggressive research and public health policy attention is placed on closing the gap between health status and health outcomes for those of low SES.

Purpose of the Study

The purpose of this study was to describe the experience of access to care among older adults receiving Medicare and Medicaid. The specific aims were to: (a) describe the experiences of accessing healthcare among older adults with government subsidized health insurance, (b) identify facilitators to accessing care, (c) identify barriers to accessing care, and (d) describe the effects of facilitators and barriers to care with regard to the participants perceptions of health.

Research Question

When little is known about a phenomenon, such as an older adult's experiences with accessing care, phenomenological research may illuminate an understanding of the phenomenon under inquiry. For that reason, the phenomenological method was the approach chosen for answering the research question: *What is the experience of access to care for older adults with government subsidized health insurance?* Encounter occurs only in dialogue and "dialogal research uncovers presuppositions most fruitfully" (Colaizzi, 1978, p. 69). Dialogal research requires the researcher be

dialogically conversant with the participant on an equal level with no social or professional stratifications. Dialogal research sets aside researcher and participant and takes place among co-researchers (Colaizzi, 1978). In this study, each participant was initially asked to verbally respond to the following statement: *Describe for me what it is like for you to get healthcare services in your community*. Additional probes were used to guide the lines of inquiry regarding their experiences with accessing healthcare services.

Descriptive Phenomenology

Phenomenology is a science of *essences*, an *eidetic science*. By virtue of its essence, Edmund Husserl (1859-1938) construed phenomenology to be “first” philosophy, free from all presuppositions, a complete reflective insight. He writes that phenomenology is a “*purely descriptive* discipline, exploring the field of transcendently pure consciousness by *pure intuition*” (Husserl, 1982, p. 136). As a method of philosophy, phenomenology is reflective and subjective in character. It is the descriptive science of experience and the matters of experience, with focus on their essential structures. For that reason, the phenomenologist is primarily interested in essential relations and structures, not in factual accounts of events (Farber, 1966). As a research method, phenomenology allows the researcher to describe phenomena as persons live them and experience them (Husserl, 1970a). Guided by the philosophical underpinnings of Husserl’s eidetic science, this study used the descriptive phenomenological approach to elicit the lived experience of accessing healthcare services by community-dwelling older adults who had Medicare and Medicaid as their source of health insurance.

As a philosophical discipline, the phenomenological method seeks to understand the events of the human experience free from all presuppositions, prejudgments, and beliefs. Husserl focused on the *uninterpreted* world of the everyday experience as expressed in common language – “*direct and immediate experience...the domain of phenomena – pure phenomena*” (Valle & King, 1978, p. 9). Pure phenomena are regardless of and before any interpretation. Pure phenomena are the *Lebenswelt* or *life-world*, the world as lived by the person, the world of lived experience. The *Lebenswelt* is the underpinning upon which existential-phenomenological thinking is built with no assumptions as to what might be the cause of the life-world; “in the truest sense, the *Lebenswelt* is the beginning” (Valle & King, 1978, p. 10).

The purpose of phenomenological philosophy is to reveal the structure or essence of experience through descriptive techniques by asking a simple question such as “What is it like to have a certain experience?” or by eliciting a response through a statement such as “Tell me what helped you to get the care you needed.” Through disciplined reflection, description is the research method, identification is the objective, and structure is the content (Colaizzi, 1978; Valle & King, 1978). The structure of the phenomenon is the “commonality running through the many diverse appearances of the phenomenon” (Valle & King, 1978, p. 16-17). Structure is the *reality* and is made present to us as *meaning*. For that reason, the role of the phenomenological researcher is “one of disclosing the nature of the structure in the form of meaning” (Valle & King, 1978, p. 17). Through in-depth descriptions, phenomenological research leads to the discovery of the concepts that give a common

meaning and understanding to the phenomenon under inquiry, in this case, access to care.

Fundamental concepts of the research method are intentionality, description, reduction, and essence (Baker, Wuest, & Stern, 1992). A core principle of phenomenology is *intentionality*, that is “human existence and the world constitute a unity, a unity so vital and basic that either one is absurd and inconceivable without the other” (Colaizzi, 1978, p. 54). In other words, every conscious act performed and every experience lived is intentional; it is “consciousness of” or an “experience of” something or other. The phenomenological use of the concept of intentionality applies to the theory of knowledge, not to human action. In phenomenology, the word means mental or cognitive intentions, the conscious relationships we have to an object (Sokolowski, 2000, p. 8).

To understand a given phenomenon in its purest form, the researcher attempts to suspend previous assumptions, presuppositions, attitudes, and biases about the phenomenon being studied. This is referred to as *bracketing*. As one brackets previous attitudes and biases, more assumptions emerge at the level of reflective awareness (Valle & King, 1978). The process of bracketing never ends. Bracketing and re-bracketing leads the researcher from the “natural attitude” to the “transcendental attitude.” Attempting to accept the transcendental attitude is *reduction* – by which the researcher “reduces the world as it is considered in the “natural attitude” to a world of pure phenomena” (Valle & King, 1978, p. 12). The phenomenological method aims to transcend the actual phenomenon and focus on the experience itself.

Reduction leads to the structure or *essence* of the phenomenon experienced. Essences are the essentials related to the true meaning of something, in other words, those concepts that give a common understanding to the phenomenon under study. Essences of the phenomenon may emerge in relationship to one another or in isolation. Ultimately, essences symbolize the basic elements of common understanding of any phenomenon (Streubert Speziale & Carpernter, 2003). According to Natanson (1973) “Essences are unities of meaning intended by different individuals in the same acts or by the same individual in different acts” (p. 14).

To know and fully understand phenomenon, the researcher begins by contacting that phenomenon as experienced by people, and gathers “descriptions” of what their experience is like (Colaizzi, 1978). The unique feature of the phenomenological method is that phenomena studied are those experienced in everyday life from the perspective of those who have lived the experience. The phenomena or experience under study is not created or experimental, it is the human experience. Since the purpose of this study was to describe the experience of access to care by older adults, the descriptive approach was chosen to answer the research question. By using the phenomenological approach, knowledge gained about access to care has come directly from the human experience of the participants, thereby enabling us to better understand the meaning of the experience in a human sense.

Phenomenological Reduction

Knowledge is built on pure data, independent of all presuppositions. Absolute data is the “pure phenomenon, that which is reduced” (Husserl, 1970b, p. 5). Reduction, as taken from the Latin word *reducere*, is the action of bringing back

(Oxford English Dictionary Online, 2004). Getting to pure data begins with phenomenological reduction, the bringing back and suspension of all beliefs that are characteristic of the natural scientific approach. It is the first step of phenomenological analysis (Husserl, 1970b). To confirm that the phenomenon is studied as it is truly experienced, the researcher must approach the phenomenon with no preconceived ideas or expectations by examining their own self-prejudices and assumptions (Cohen, 1987).

Husserl (1970b) used the term *bracketing* to describe how the phenomenological researcher must set aside any preconceived assumptions and suspend every such belief to more fully explore the meaning of the experience as described by the person. Separation of pure phenomenon, as opposed to what is already known about the phenomenon under study, is the goal of phenomenological reduction. Bracketing, therefore, is essential in phenomenological research if descriptions of the phenomenon are to achieve their purest structure (Streubert Speziale & Carpernter, 2003).

To fully understand the phenomenon under study in its purest form, the researcher must eliminate or ‘bracket out’ any preconceptions and presuppositions prior to beginning the research. In this study, the researcher presupposed that older adults with government-subsidized health insurance experienced numerous obstacles in their attempt to access healthcare services. This presupposition lead to the belief that older adults with Medicare and Medicaid are more likely to receive poorer quality of healthcare and thus poorer health outcomes than their more affluent counterparts.

Reviewed studies of health disparities among low-income older adults have shown that functional limitations, multiple co-morbidities, fewer social support systems, lower level of education, and lack of resources and services have a negative influence on health status and health outcomes. Living in poverty is the single, socioeconomic factor that most consistently relates to whether or not a person will experience some form of adverse health event and/or disparity in treatment.

Essentially, this researcher remained as neutral as possible with respect to previous attitudes and biases regarding the phenomenon studied. Examining preconceived ideas, expectations, and prior knowledge about access to care, prior to initiating the study assisted the researcher to study the phenomenon as it was truly experienced by those interviewed. Bracketing allowed the researcher to be fully open to the experience as described by the informants and began the reductive process. Bracketing was an ongoing practice throughout the investigation.

Significance of the Study

Current federal efforts and other important initiatives have focused on the need to reduce and ultimately eliminate health disparities by directing researchers to explore an understanding of societal and structural phenomena such as poverty, access to care, education, race and ethnicity, social status, and environmental factors, and the role they play in health disparities found in vulnerable groups (Agnew, 2000; Clinton, 2000; Flaskerud et al., 2002; Flaskerud & Nyamathi, 2002; Gotsch, 1999; Henderson, 2000; NIA, 2000; NIH, 2000). Health disparities are prevalent among vulnerable populations, especially those who are socially and economically disadvantaged. The fact that major illnesses such as cancer, cardiovascular diseases, and diabetes have

specific pathogeneses suggests the need to explore further peripheral issues and underlying experiences that may relate SES to health disparities. Reasons for unhealthy lifestyle behaviors such as smoking, alcohol consumption, and poor diet, found to be more prevalent among those of lower SES, remain significant and unanswered issues (Cohen et al., 2003).

Indicators of SES such as income, occupation, and education have persistently been recognized as strong determinants of playing significant roles as social causes of health disparities among disadvantaged groups (Guralnik, Land, Blazer, Fillenbaum, & Branch, 1993; Link & Phelan, 2000). The relationship between SES and other conditions that lead to poor health and less than optimal quality of life has been well documented in the research literature (Evans et al., 1994; Feinstein, 1993; Flaskerud et al., 2002; Flaskerud & Winslow, 1998; Geronimus, 2000; Lantz et al., 1998; Wong, Shapiro, Boscardin, & Ettner, 2002). None-the-less, researchers to date have failed to adequately address *what* and *how* social, political, economic, and environmental risk factors contribute to poor health, disease, and even premature death.

Feinstein's (1993) critique of the literature found researchers to be "far better in documenting the existence and extent of health inequalities than in explaining why these inequalities persist" (p. 280). One explanation given was differences in access to and utilization of formal services within the healthcare system, but little was known just how much these factors contributed to inequalities. Bassuk, Berkman, and Amick's (2002) longitudinal study confirmed income was most consistently associated with mortality among older women and men, since income is believed to promote greater access to material necessities and services. The longitudinal survey done by

Lantz et al. (1998) concluded that socioeconomic differences in mortality would continue to persist even with improved health behaviors among the disadvantaged because of other mitigating factors.

Quantitative studies have provided indices such as these discussed and other data about barriers to care and type and frequency of access to care (Bierman & Clancy, 2001; Bierman, Magari, Jette, Splaine, & Wasson, 1998). Researchers have been challenged with the task of developing appropriate strategies and action plans to eliminate health disparities among the United States most vulnerable groups (Clinton, 2000). Flaskerud et al. (2002) reviewed 50 years of *Nursing Research* publications on health disparities and found research methodologies focused primarily on the empirical design and called for studies that used participatory methods. In an earlier article, Flaskerud and Winslow (1998) suggested research designs move away from the traditional methods of epidemiological studies to include qualitative designs, action research, and feminist methods. They argued that these approaches would provide an opportunity for understanding the experiences of vulnerable groups and factors that contribute to vulnerability.

Kneipp and Drevdahl (2003) pointed out that just as no one factor or indicator would determine the cause of health disparities, no one method could give researchers a deeper understanding of the reasons for health disparities. They challenged the need for qualitative methods to “give meaning to findings, assist with developing theoretical and methodological foundations for new approaches, and provide guidance for interventions” (p. 169). Qualitative methods, such as phenomenology, have allowed researchers to document and describe human expression and human emotion.

This approach has often provided insights that escape the statistical findings of quantitative methods. Utilizing the phenomenological approach allowed this researcher to describe the phenomenon of access to care as expressed by those living the experience. This study began the process of developing knowledge to better understand the meaning of *what* it is like for community-dwelling older adults with Medicare and Medicaid to access healthcare services.

A current review of the literature revealed no qualitative study that had described the lived experience of access to care by a population whose demographic characteristics were similar to those studied. This study documents a qualitative description that is now absent in understanding such a person's experiential world about accessing care within the structure of our current healthcare system. Recounting lived experiences through the participants' narratives has offered personal meaning about access to care and barriers to care that standardized questionnaires and surveys were unable to provide.

Chapter II

Context of the Inquiry

What bedevils the poor, as Cora Jackson could attest, are Medicare's gaps. It does not pay for medication, for transportation, for many basics that may sound wholly affordable to those with generous pensions or insurance to supplement Medicare. But such essentials strap the poor, who often end up going without (Abraham, 1993, p. 4).

This chapter provided the background for the purpose of establishing the need to explore the meaning of access to care among low-income adults living in the community and who receive Medicare and Medicaid. A vast majority of white Americans believe that all Americans should and do enjoy the equal opportunities of job, income, education and healthcare (Morin, 2001). Unfortunately, this ideal falls far short from reality, since overwhelming evidence has continued to show that disadvantaged minority groups receive poorer healthcare and experience poorer health outcomes than whites (Auchincloss et al., 2001; IOM, 2002; Scheifer et al., 2000).

Access to quality healthcare is a leading indicator to reducing and ultimately eliminating health disparities among vulnerable groups. Impoverished older adults are a group that are generally acknowledged as being vulnerable, that is, a group who may be more susceptible to or at higher risk for adverse health outcomes (Aday, 2001; Flakerud & Winslow, 1998). Review of the literature revealed no qualitative study used the phenomenological approach to explore and describe the phenomenon of access to care among this vulnerable population subgroup. As a result of this gap in the research, little was known about the lived experience of access to care by older adults with government-subsidized health insurance.

Consequently, the following literature review was only able to capture the quantitative perspective concerning factors shown to have had some adverse effect on the health status of low-income older adults. As noted earlier, SES, gender, race, and ethnicity are closely associated with access to resources and viewed as potential fundamental causes of disease. The reviewed quantitative studies were grouped according to socioeconomic resources (human capital, social support, and social status) and environmental resources (healthcare quality and access to care). Healthcare insurance was included in environmental resources. In keeping with qualitative inquiry, additional inquiries in the literature were reviewed following data collection and analysis (Swenson, 1996).

Vulnerable Populations Model

Aday's (1993) sociological model for studying vulnerable populations provides a framework for examining the social determinants of vulnerability and for organizing and understanding the range of disparate data on the health and healthcare

needs of vulnerable populations. Aday's underlying theory asserts that vulnerability to poor health does not characterize personal flaws on the part of those individuals within vulnerable groups. Instead, the model reflects the interrelated effects of many factors (individual assets, social assets, and demographic factors) over which persons have little control, but that do play a role on the development of health risks. The model points to society's responsibility to provide appropriate health services to prevent illness and promote health in vulnerable population groups (Sebastian, 1999).

Although some groups have been targeted as being more vulnerable than others, Aday (2001) contends, "as members of human communities, we are all potentially vulnerable" (p. 1).

The vulnerable populations framework proposes a direct relationship between the concepts of resource availability, relative risk, and health status. Flaskerud and Winslow (1998) expanded Aday's (1993) framework by focusing on the relationship between the three concepts. The relationship between resource availability (societal and environmental resources) and relative risk proposes that decreased or lack of resources results in an increased exposure to risk factors. The relationship between relative risk and health status (measured by morbidity and mortality rates) is that an increased exposure to risk factors increases the morbidity and mortality rates of a population. The inverse is also true, that is, health status has a direct effect on relative risk. The relationship between health status and resource availability indicates that increased morbidity and mortality leads to a depleted resource pool. Consequently, the interaction effects of the three concepts can result in a greater or lesser propensity for health disparities and poorer health-related outcomes among vulnerable groups.

Resource Availability

Link and Phelan (1995) have argued that fundamental social causes of disease are specifically linked to the availability of resources that can be utilized to avoid risks or minimize the consequences of disease processes. Resource availability is the accessibility of socioeconomic resources (human capital, social support, and social status) and environmental resources (healthcare quality and access to care) (Aday, 2001; Flasterud & Winslow, 1998). Resources may include money, power, knowledge, prestige, and interpersonal social connections. Variables such as SES, gender, race and ethnicity are closely associated with access to these resources and therefore should be viewed as potential fundamental causes of disease. Generally, researchers have tended to focus on individually based risk factors, such as genetic factors and unhealthy lifestyles, as the causal link in the disease process. However, centering on this viewpoint may circumvent important sociological processes in the causal chain to disease and ill health (Aday, 2001; Link & Phelan, 1995, 2000).

Relative Risk

Relative risk is described as the ratio of the risk of poor health among groups who are exposed to risk factors compared with those groups who are not exposed. Risk factors may include behaviors such as alcohol abuse and smoking or environmental exposures that are associated with increased incidence of adverse health-related outcomes. Individuals and communities at risk are more susceptible to harm or neglect and less resilient to unfavorable events due to lower SES, lack of support systems, and fewer resources (Aday, 1993).

Health Status

Health status encompasses the physical, psychological, and social health needs of the community and the individual. Community health needs assessments may focus on the prevalence of certain chronic diseases, disabilities, and ADL limitations within older adult subgroups. Individual's health needs assessment concentrate on measuring the health status of individual residents within a community based on disease specific incidence. Community needs are primarily influenced by governmental health policy initiatives, whereas needs of the individual are the concern of personal healthcare delivery and practice (Aday, 1993).

Concepts Relevant to the Phenomenon Under Study

Access to Care

The Institute of Medicine (IOM) defines access as “the timely use of personal health services to achieve the best possible health outcomes” (IOM, 1993, p. 4).

Important to this definition is that utilization of health services and health outcomes serve as indicators to measure whether access has been achieved. Stevens (1992)

defines equitable access to healthcare by the following conditions:

- (a) Relative costs of healthcare are experienced equally across all groups, (b) healthcare availability is based on the health needs and geographic distribution of the population rather than on the distribution of wealth, (c) healthcare encounters are of equal quality and comprehensiveness across all groups, and (d) healthcare interactions are positively perceived by all groups of clients so that continuing utilization of healthcare systems is facilitated (p. 187).

Equitable access involves deciding whether there are systematic disparities in utilization and outcomes among specific social groups and whether the disparities result from financial barriers or other barriers to care. Lack of transportation, language difficulties, and low educational levels are some of the barriers that make gaining access to the healthcare system a complex endeavor for many who are already in compromised situations. The overall purpose of gaining access to the healthcare system is not only for treatment of acute symptoms and to avoid premature death, but to increase the years of healthy life and maintain long-term functional status (IOM, 1993).

Health Disparities

Health disparities are described as “differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States” (NIH, 2000, p. 4). Disparities in health status among vulnerable groups have persisted into old age despite the advances that have been made in healthcare technology. Among these vulnerable groups are the socioeconomically disadvantaged elderly, who in the face of advanced technology have continued to experience major disparities in health for conditions such as cancer, cardiovascular diseases, and diabetes (Cohen, Farley, & Mason, 2003; Cohen, Mason, Bedimo, Scribner, Basolo et al., 2003; Gotsch, 1999).

Vulnerable Groups

Vulnerable and at-risk populations are those groups in our society who may be more susceptible to or at higher risk for experiencing adverse outcomes regarding their physical, psychological, or social health (Aday, 2001; Flaskerud & Winslow, 1998;

USHHS, 2001b). Overlapping boundaries between physical, psychological, and social health have put an individual and/or group at even higher risk for health disparities. In other words, poor physical health is likely to be compounded by poor psychological health and/or poor social well-being and vice-versa (Aday, 1999). Social and structural risk factors such as pervasive poverty, inadequate housing, homelessness, inferior social status, disrupted social networks, and fewer environmental resources have also been identified as contributing to an increased propensity for illness, disease, and poor health (Evans, Barer, & Marmor, 1994; Link & Phelan, 1996).

Groups traditionally acknowledged as vulnerable include the impoverished; those who are chronically ill or disabled, including those with mental illness; people who experience prejudice and are considered inferior; people who are politically marginalized and deprived of their civil and human rights; and alcohol or substance abusers (Aday, 2001; Flaskerud & Winslow, 1998; Link & Phelan, 1996). Vulnerable groups usually include the elderly, women, children, ethnic peoples of color (African American, Hispanic, Native American, Asian American), homeless persons, immigrants and refugees, abusive families, and gay men and lesbians (Aday, 2001; Flaskerud & Winslow, 1998). Health needs are greatest for those persons or groups who experience overlapping boundaries between physical, psychological, and social health.

Literature Review

Socioeconomic Resources

For a period of time especially in the late 1960's and early 1970's, researchers assumed that health inequalities associated with SES would diminish due to advancing

medical technology and a more affluent society in developed countries. However, by the late 1970's and early 1980's, it became apparent that there remained a gap in the association between health and economic equality, and that the health status of populations even in developed societies had not improved (Robert & House, 2000). Pappas, Queen, Hadden, and Fisher (1993) found that the inverse relation between mortality and SES not only persisted in 1986, but also was even stronger than in 1960. These researchers concluded, "despite an overall decline in death rates in the United States since 1960, poor and poorly educated people still die at higher rates than those with higher incomes or better educations" (p. 103). In the United States, research of socioeconomic disparities in health has relied on income and education as the more widely used indicators for determining socioeconomic position. This is because education and income have the characteristics of applying to all people and is continuous in nature (Robert & House, 2000). The following studies corroborated the inequalities found in health status among those within a lower socioeconomic position living in the United States.

Human capital. Developing human capital is the positive result of changing people by giving them the skills and capabilities that make them able to act in new ways. Human capital can be viewed or defined as an individual's or groups income, occupation, education, and housing status (Coleman, 1990; Flaskerud & Winslow, 1998). The lack of human capital, commonly characterized by SES, is one of the most consistent findings addressed in epidemiological research and represents significant differences among people that can be correlated with health and life expectancy (Lynch & Kaplan, 2000).

Higher education is associated with lower morbidity and mortality because it promotes access to and the ability to use health-relevant information, including participation in preventive health services. Those with lower education are not so fortunate. For example, Geller et al. (1996) found that lower education was associated with decreased survival for melanoma patients and Liao, McGee, Kaufman, Cao, and Cooper (1999) associated lower education with a higher incidence of morbidity and disability in the last years of life. Lower education may produce health behaviors that delay seeking healthcare at early onset of symptoms, thus resulting in more advanced stage and disability at presentation. Research indicates the educated are more likely to access medical care more frequently and utilize medical specialists more often.

Liao et al. (1999) found people with higher SES, as characterized by higher educational achievement, experienced lower morbidity and disability in the last years of life compared to those with fewer years of education. The study used data (N = 10,932) from the National Health Interview Survey (1986-1990) and analysis of covariance to test for significant differences in the morbidity/disability indexes among three educational categories (0-8 years; 9-12 years; > 12 years), with log-transformation for number of conditions, bed days, and hospital days. The statistical program SUDAAN was used to report the data. Baseline information was collected and followed by periods of: death within 1-year; death within 1-2 years; and death after 2-years. Educational achievement was inversely associated with long-term limitation of activity, number of chronic conditions, number of bed days, and days of short hospital stay. The implication is that since there is no biologic reason associated with educational achievement, lower morbidity and disability should be a

characteristic experienced by the total population. For that reason, if some of the population can experience a reduction in morbidity and disability, such as those with higher SES, then why not all?

Participation and contact with a greater number of risk factors are also correlated with patterns of increased morbidity and premature mortality particularly in disadvantaged populations. Race and female-headed households are strong predictors of premature mortality, but chronic unemployment, geographic location, low education, and the lack of available health services are also influential factors (Mansfield, Wilson, Kobrinski, & Mitchell, 1999). Mansfield et al. calculated years of potential life lost to measure premature mortality at the county level ($N = 3,073$) and to show where the health of populations in the United States is the poorest. Premature mortality was measured as life-years lost before the age of 75 because this age approximated the current life expectancy in the United States at the time the study was conducted. Race classification was: White; Black; Hispanic; American Indian; and Asian/Pacific Islander.

A multiple regression model was used to explore the effects of socioeconomic and health resources on premature mortality. The researchers concluded that community structure factors such as those noted and other factors such as local government spending, local welfare spending, and vacant housing, statistically explained the variation in premature mortality and called for the need for further investigation. How and why community structure factors play a role in premature mortality was not explained. The authors propose, “as federal and state policymakers seek to improve health, they should consider whether resources might not be better

spent on programs to reduce social pathology (e.g., education, job training, economic development, and adolescent pregnancy prevention) instead of on more medical care” (p. 898). The data suggest a stronger focus on health promotion and illness prevention strategies.

Social support. Williams (1990) review of the literature on the relationship between SES and physical health status suggested important links between health behaviors, stress, social ties, and attitudinal orientations in relation to social structure and health status. Social support relationships and networks are psychosocial factors identified as having a beneficial effect on the health status and health outcomes of elderly people (Choi & Wodarski, 1996). The effects of social support can be especially important for those coping with debilitating chronic illness on a daily basis.

Tanner and Feldman (1997) found social support to be an important factor associated with keeping medical appointments for low-income elderly people with chronic illness (N = 200). This intervention study showed significantly greater appointment keeping by those who received social support interventions (social support counseling, attending appointment with significant other, postcard reminder, telephone call to significant other) than those who did not. Social support included a family member, significant other, and/or clinic staff. It is important to note that clinic staff was considered social support. Clinic staff can have a significant impact on encouraging and assisting elderly persons, who in many cases have no family or significant other, to more easily access the healthcare system.

Social status. Social status is associated with the hierarchical rank that individuals hold in society as a result of gender, race, or age, and the socially defined

opportunities and rewards that occur as a consequence. Four main components of social status can have an affect on health: education, employment, work conditions, and economic well-being. Differences in the components create differences in health, which can ultimately affect a person's quality of life over the course of the life-span (Mirowsky, Ross, & Reynolds, 2000). The social advantages acquired by those with money, power, knowledge, and prestige, have enabled those persons to avoid health hazardous risk factors more readily and incorporate health promotion strategies into their daily lives (House et al., 1990). For those of lower social status, chronic diseases, functional impairment, lower life expectancy, and higher death rates are more prevalent (Geller et al., 1996; Pappas et al., 1993; Williams, 1990).

Despite the declines in the incidence of cardiovascular disease (CVD) over the last 30 years, heart disease continues to rank as the leading cause of death for those 65 and over (National Center for Health Statistics, 2001). Sundquist, Winkleby, and Pudaric (2001) examined the association of ethnicity on CVD risk factors and health behaviors among black (n = 700), Mexican-American (n = 628), and white (n = 2,192) older men and women. The Third National Health and Nutrition Examination Survey (NHANES III), 1988-1994 collected health status data via standardized questionnaires; physical examination and laboratory testing were done via mobile examination centers. Risk factors used as outcome variables were, type 2 diabetes, physical inactivity, abdominal obesity, hypertension, smoking, and non-high-density cholesterol (non-HDL-C). Level of education was used as the SES indicator. Primary analyses using multiple regression models were carried out in the SUDAAN statistical software to adjust for the complex sample design of NHANES III.

Results showed higher levels of poverty among both black and Mexican-American women and men than among their white counterparts and were paralleled by their lower levels of education. Ethnicity was significantly associated with CVD risk factors. For example, black and Mexican-American women had significantly higher prevalence of type 2 diabetes than white women. Black women were significantly more likely to be physically inactive, have abdominal obesity, and hypertension than white women. Black men had significantly higher prevalence of physical inactivity and hypertension than white men. Among the women in general, lower SES was significantly associated with higher prevalence of type 2 diabetes, physical inactivity, and abdominal obesity, and in men with physical inactivity and smoking. Mexican-American women were significantly less likely than black and white women to monitor for diabetes, make efforts to lose weight, and comply with medication recommendations. Overall, black and Mexican-American women and black men were found to be at greatest risk for CVD.

The results of this study suggested the need for educational strategies targeted towards improving health behaviors and establishing appropriate primary and secondary prevention programs. But to be most effective, educational programs must be modified for the language, cultural, and medical needs associated with older ethnic minorities. This study failed to show an understanding as to why there was a higher prevalence of CVD risk factors among poor ethnic minorities who have lower level education status.

Analysis and Critique: Socioeconomic Resources

A lack of socioeconomic resources (human capital, social support, and social status) may be deterrents for a person being able to avoid health risk factors and minimize illness and disease. Education is the core component of social status because it determines the likelihood of being employed, the quality of the jobs the person can occupy, and the amount of income that can be generated over the person's life span. Education is an essential determinant of the social distribution of health and well-being. Poorly educated people are more likely to be unemployed, have less fulfilling, more routine, and dangerous work. With lower income, poorly educated people experience more economic hardships. Overall, the poorly educated have less control over their own lives, practice poorer health habits, and have less social support (Mirowsky et al., 2000).

Social support is a significant resource for individuals in coping with and lessening the impact of negative life events and adversity on physical and mental health. Physical, psychological, and social health is directly improved for people with supportive social networks (Aday, 2001). In contrast, poor social support may lead to a person not keeping medical appointments, to being non-compliant with recommended treatments, or to delaying diagnosis of a disease process. Delaying treatment or non-compliance with treatment may lead to further disability, isolation, and premature death. Lower education, language barriers, and differences in cultural practices are also factors that are likely to influence a person's decision to access medical services. These factors may also have a direct impact on an individual's ability to comply with recommended health practices and treatment modalities.

Because poor health may result in lower income, Liao et al. (1999) looked at educational achievement as the indicator for SES. Persons of lower SES are more likely to have been deprived of the benefits of adequate and appropriate healthcare in their earlier years, resulting in susceptibility to increased incidence of chronic conditions and disability in later life. The study's large sample size ($N = 10,932$) and high response rate (96%-98%) allowed the results to be more generalized. Household interviews included proxy interviews so ill and disabled persons were also included. However, the use of secondary analysis can present limitations to the secondary investigator (Liao et al.) since there is no control over how the initial data was collected (Powers & Knapp, 1995).

Mansfield et al. (1999) used eleven variables to determine premature mortality before the age of 75. The data represented nearly all the counties in the United States ($N = 3,073$) and 248 million people. An admitted limitation was assuming homogeneity in SES and resource characteristics in each county. As a result, characteristics of individuals, their access to care, and age at death were not linked. In addition to other variables, education in this study was determined to be a strong predictor of early death.

Education was also a preferred measure of SES by Geller et al. (1996) who studied mortality among the socioeconomically disadvantaged with melanoma. Their analysis resulted in several revealing findings concerning disparities in health status and health outcome among particular vulnerable persons who presented with melanoma. That is, higher mortality/incidence ratios were associated with lower SES;

persons of lower SES were at more advanced stage disease at diagnosis; and lower education was associated with decreased survival rate.

Declines in mortality from CVD have been slower in black than in white populations and in lower SES than in higher SES populations. In the national sample of older women and men studied by Sundquist et al. (2001), black and Mexican-American women and black men demonstrated the highest prevalence of CVD risk factors after accounting for age and SES. The higher CVD risk factors in older ethnic minorities indicates the need for equal access to healthcare and the need for healthcare professionals who are conscientious of these patients' special needs especially with respect to language barrier and cultural practices.

Social networks and social support for health can be beneficial factors in slowing the deterioration of an older adult's health. Providing some form of social support allows the older adult with chronic illness and disability to better cope with the long-term nature of such physical problems. With increasing life expectancy comes the increasing number of people who may out-live many friends and even family members. Social support is an important link in assisting this vulnerable group easier access to the healthcare system and ensuring quality care for both prevention and treatment of illness and disease (Choi & Wodarski, 1996; Tanner & Feldman, 1997).

Environmental Resources

Access to Care

Adequate access to healthcare extends beyond financial ability to pay, insurance status, and adequate numbers of health providers. Strong determinants that

can affect access to healthcare services may include personal characteristics (disability status, income, and private health insurance), structural characteristics (geographic distribution, availability of providers, and population density), and neighborhood characteristics (high poverty rate and high proportion of older persons) (Auchincloss, Van Nostrand, & Ronsaville, 2001). Auchincloss et al. found that having Medicare does not necessarily eliminate access to care problems. This study used the 1994 National Health Interview Survey (NHIS), people ages 65 and older ($n = 12,341$), the 1990 census block group data, and 1994 data on health professional shortage areas (HPSA). Logistic regression was used to model the probability of problems accessing care.

Overall, 13.7% of the participants reported access problems. Persons who were Black, living alone, disabled, had low education, low income, or no private health insurance had higher rates of access problems than their peers. People who had Medicaid as a secondary coverage remained at significant risk for poor access as compared to those with private insurance. Living alone increased an older person's risk for access problems by 56% compared to those living with others.

Needing assistance with at least one ADL, or a combination of at least one ADL and instrumental activity of daily living (IADL), increased access problems by 39% compared to those not needing assistance. Older persons living in poor neighborhoods had an increased probability of access problems compared to those living in wealthier neighborhoods. Utilizing personal, structural, and neighborhood characteristics, this study established clear factors that contribute to older persons

inability to receive medical care in a timely manner. However, the personal impact that these factors have on older persons remains unknown and unanswered.

Disadvantaged or vulnerable populations are generally thought to be at higher risk for postponing care for conditions that eventually lead to hospitalization and potentially to poorer health outcomes. Delaying care for illnesses may result for various reasons. Being poor, lack of knowledge regarding disease process, financial barriers, gender and race may be some of the reasons for postponing care. Delayed hospital presentation for acute myocardial infarction (AMI) was identified by Sheifer et al. (2000) among Medicare beneficiaries living in poor neighborhoods. This study used data from the Cooperative Cardiovascular Project between January 1994 and February 1996 (N = 102,339). Patient characteristics were tested for associations with late presentation by use of backward stepwise logistic regression.

Late presentation was defined as presenting six hours or more after symptom onset. Factors associated with delayed presentation were being female, black, living in an impoverished area, having co-morbidities such as diabetes and prior angina, presenting to an outpatient clinic for initial evaluation, and arriving during the daytime hours. Given the associated factors found to contribute to delayed presentation, the researchers suggested education efforts directed toward earlier AMI treatment for people who are at risk for delay. But the study does not address *how* these factors essentially contribute to delayed care for AMI or explain *what* about these factors that contribute to the delay.

Healthcare Quality

Studies have demonstrated that quality of healthcare can vary according to racial characteristics, ethnicity, and poverty status. Blacks and Hispanics are generally found to receive lower quality of care than the non-minority white population. Studies that include Asians and Native Americans also indicate the same discrepancies in care (IOM, 2002; Kahn et al., 1994; Saha, Arbelaez, & Cooper, 2003; Schneider, Zaslavsky, & Epstein, 2002; Virnig et al., 2002).

Respondents from the 80+ Project's survey who experienced financial difficulty and ADL limitations were identified as being at increased risk for encountering barriers to healthcare primarily due to cost (Bierman et al., 1998). Adding to the insult of financial and structural barriers to accessing care can ultimately result in further adverse health outcomes. A telephone survey (n = 834) was conducted to assess health and functional status, access to care, patient satisfaction, and utilization of services. A mail survey (n = 636) assessed six domains of functional health and prevalence of common geriatric problems. Logistic regression was used to report the data.

Individuals reporting financial difficulty were eight times as likely to have delayed care because of cost. Those with ADL limitations were twice as likely to report having trouble getting care or delaying care because of cost. Respondents of these subgroups (financial difficulty and ADL limitations) reported more difficulty getting appointments, getting after hour advice, and seeing a specialist. The respondents also reported less satisfaction with quality of care due to their more frequent encounters with experiencing barriers to care. Both subgroups were more

likely to feel their doctor could not figure out what was wrong with them and individuals with financial difficulty felt their care could be a lot better. The authors suggested, “assessing patient-physician interaction from the perspective of the patient may provide insights into this essential link between access, quality of care, and health outcomes” (p. 24). The use of qualitative methods in future research would be an appropriate approach for exploring the phenomenon of the patient-physician relationship from the perspective of the patient.

Healthcare Insurance

Few researchers and healthcare professionals would argue that having some form of health insurance is an essential component to accessing the United States healthcare system and improving health outcomes. Studies show that differences in type of healthcare coverage can also determine differences in the course of treatment for some people. Medical procedure use for people presenting with cardiovascular (CV) disease varies significantly according to patients' SES and type of health insurance coverage (Carlisle & Leake, 1998). Worse physical health outcomes are more common among Medicare elderly and poor chronically ill people who access health maintenance organizations (HMO) than those in fee-for-service (FFS) plans (Ware, Bayliss, Rogers, Kosniski, & Tarlov, 1996).

Carlisle and Leake's (1998) cross-sectional analysis during a three-year period of 206,233 ischemic heart disease patients living in California showed the utilization of three invasive CV procedures (coronary angiography, bypass grafting, and angioplasty) varied significantly by patients' SES areas. Medicare beneficiaries made up 51% of the study population. Multiple logistic regression was used to compute the

odds of receiving each procedure. Medicare beneficiaries of low SES areas and without Medicaid were less likely to undergo each of the CV procedures than those of higher or middle SES areas. The findings add to the body of evidence that nonclinical factors do play a role in determining whether a particular patient does or does not receive a specific medical service. The researchers suggest the responsibility of co-payments and deductibles associated with having Medicare only may be a deciding factor in a patient choosing to have such a procedure. However, similar results were found among HMO patients. The decision-making process among older adults concerning such procedures remains unknown and warrants further investigation.

Ware et al.'s (1996) four-year longitudinal study included 2,235 patients diagnosed with hypertension, non-insulin dependent diabetes mellitus (NIDDM), recent AMI, congestive heart failure (CHF), and depression. Summary physical and mental health scales from the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) was used to collect baseline and four-year follow-up scores. The objective of the study was to compare physical and mental health outcomes of chronically ill adults, including elderly and poor subgroups, treated in HMO and FFS plans. At baseline collection, 36.8% of the study participants were 65 years or older; 54% were female; about 22% were at or below the 200% poverty level; and 16% of those were covered by Medicaid. Medicare beneficiaries (65 years and older) and low-income patients (200% of poverty) were analyzed separately. Results showed declines in physical health to be more common for Medicare patients in an HMO than in a FFS plan. Mental health outcomes were better at one HMO site, but not at two others. For those of poverty status, outcomes were better in FFS plans, but for the non-poverty

group, HMO plans were favored. This study failed to report why these discrepancies occurred and only suggested that healthcare plans carefully monitor the health outcomes of these vulnerable population subgroups. Further research regarding *how* and *what* among the variables may lead to interventions that provide better health outcomes.

Lum and Chang (1998) examined the effect of supplemental Medicaid coverage on the utilization of health services by low-income elderly people with Medicare in three areas of service: home health, physician visits, and inpatient hospital days. Data were used from the Asset and Health Dynamics among the Oldest Old Study (AHEAD) and included only low-income older adults over the age of 70 (N = 1,542) with an income at or below 120% of the federal poverty threshold. Descriptive statistics were obtained on all the variables for the sample. Findings showed that having Medicaid coverage generally improved healthcare access by improving the affordability of health services.

About 16% of low-income the older adults used home health services and more than 86% had physician visits in the 12-month period before the AHEAD interview. About 25% used hospital services the year before and Medicaid covered 20% of the respondents. Of the Medicaid recipients, about 21% were African-American and about 9% were Hispanic. Compared to those without Medicaid coverage, those who had Medicaid coverage were twice as likely to use home health services, 1.9 times more likely to make physician visits, and 2.1 times more likely to use hospital services.

Health service use also varied by race, ethnicity, and gender. African American women used home health services more; white women used hospital services more; and Hispanic men used both services more. Among those who used hospital services, fewer hospital nights were reported for African-American men. More physician visits were reported among African-American women and white women. The variation in utilization of services among the groups is an area in need of further investigation.

Analysis and Critique: Environmental Resources

Equal opportunity to obtain environmental resources (access to care, healthcare quality, and healthcare insurance) is essential to closing the healthcare gap that continues to exist among populations in the United States. Factors linked to environmental resources such as inappropriate or lack of transportation, living alone, needing assistance with ADLs and IADLs, or living in a poor neighborhood significantly decrease an older person's ability to access healthcare resources. Support from neighbors whom share similar ancestry, race, or ethnicity may have an influence on access to care (Auchincloss et al., 2001). Support from peers in accessing care instead of family members or significant others, is also an area that may prove worthy of further investigation.

Bierman et al. (1998) identified barriers to care that limited access for people age 80 and older. Their findings showed that people who experienced financial difficulty and ADL limitations were especially vulnerable for encountering barriers to healthcare and were more likely to report less satisfaction with the quality of care received. They admitted, "the ability to improve health outcomes through reducing barriers to care is dependent on the effectiveness and quality of care received" (p. 24).

The data was limited by the small geographic area (New England) and two facilities. Respondents were predominately white, fairly well educated, and the majority reported no financial difficulty. These variables raise issues of generalizability to other populations, particularly those who are in vulnerable population subgroups.

Research has not yet determined why people of a particular race and ethnicity or lower SES experience more difficulty in accessing care or experience poorer quality of care. But, research to date strongly suggests that health disparities continue to exist. Prompt treatment is vital to the successful management of AMI. Identifying individuals who may be at highest risk for late arrival for treatment of AMI is necessary to increasing the number of people who can benefit from this knowledge. To evaluate socioeconomic factors, Sheifer et al. (2000) tested for associations between time to presentation and residence in an impoverished area.

Limitations to the data were identified. The use of zip codes to evaluate poverty status assumes all people living in impoverished areas are really poor, which is not necessarily true. Also using a large study population ($N = 102,339$) and an expansive pool of candidate predictor variables (race, sex, age, and “off hour” presentation) may show statistical significance, but clinical insignificance. The authors suggest health education efforts be directed towards individuals identified at highest risk (female, black, living in poor area, and co-morbidities). Barriers such as cultural differences, social support, and educational status should also be addressed in an effort to improve early intervention for people at highest risk for delaying treatment for AMI. Modified educational approaches may be required, in addition to providing practitioners familiar with cultural differences and practices (Sheifer et al., 2000).

Although government subsidized health insurance provides more people the opportunity to access care, it does not necessarily mean equitable care will be provided. Carlisle and Leake (1998) used California zip codes to evaluate the use of CV procedures by residents who lived in areas considered to be of low, middle, and high SES zip code status. The use of zip codes assumes a person is of a particular SES and may pre-determine whether or not a person will be offered a costly procedure. Their study purpose was to confirm the effect of SES as a predictor of procedure use and examine whether this effect was consistent across different health insurance categories. Findings showed the odds of receiving a procedure increased with SES and the effect of SES on procedure use varied by health insurance category. Medicare recipients were particularly vulnerable financially in ability to access these procedures since co-payments and deductibles were generally required. Implications for future research may include direct dialogue with patients to understand how treatment decisions are made and with physicians to understand judgment regarding appropriate treatment measures.

Reported discrepancies in health status (Ware et al., 1996) and healthcare service utilization (Lum & Chang, 1998) among Medicare recipients are also areas for further investigation. Co-payments and deductibles for general health maintenance and no coverage for specialty services, such as dental and vision care, preclude many older adults from seeking services that would significantly improve quality of life. These are issues that go hand-in-hand, as one cannot be solved without the other being addressed simultaneously. Given the reported discrepancies, Lum and Chang (1998) suggested higher priority be given to restructuring and integrating the benefit packages of

Medicare and Medicaid to provide better healthcare to low-income older adults. Knowledge concerning these issues is necessary for policymakers to adequately address healthcare services for this group.

Synthesis of Literature Review

Despite all the research conducted about socioeconomic and environmental disparities in health, much remains to be studied. Thus far, evidence has shown that many factors not directly related to medical need influence the use of health services, which in due course effects health status. Race, ethnicity, SES, health insurance status and type, and residing in a particular area are some such factors (Auchincloss et al., 2000; Carlisle & Leake, 1998; Sheifer et al., 2000). Within the vulnerable populations model, resource availability is conceptualized as the availability of socioeconomic and environmental resources (Flaskerud & Winslow, 1998). The availability of resources is by far a major focus of investigation among researchers. But, resource availability issues encompass multiple complex variables making it difficult to isolate which factors are definitive determinants that result in health disparities among the low-income older adult and other vulnerable population groups.

The studies reviewed emphasize the paradox between the ‘haves’ and the ‘have nots’; that is, those with the fewest resources to negotiate the healthcare system seem to have the highest burden of disease, illness, and unfortunately premature death. Within American society, income is generally viewed as a means to better health because income provides access to material resources and services even after a person has reached the age of retirement. The disparities between the ‘haves’ and the ‘have nots’ is especially evident in a population’s general well-being and health outcomes.

In other words, those who are more advantaged socially and economically have greater access to resources and are less afflicted by risk factors that may lead to poorer health outcomes than their more disadvantaged counterparts (Bassuk et al., 2002; Bruder, 2002; McCally et al., 1998).

Other gaps in resource availability may be found in healthcare organizations and payment systems (Bierman & Clancy, 2001). Healthcare organizations may exclude the less educated client from actively participating in care by the sheer size and complexities presented by the system. Financial gaps in private and public payment systems exclude reimbursement for preventive services which may result in delayed treatment and lead to chronic illness and disability. Chronic illnesses and disabilities that could be minimized or prevented with earlier presentation to the healthcare system deplete the pool of precious resources for all the population and deprive people of increased quality and years of healthy life.

The vulnerable populations' model also suggests that a lack of socioeconomic and environmental resources has led to increases in relative risk and exposure to risk factors. Cumulative levels of stress as a result of situations such as lower occupational status and chronic unemployment may also contribute to early onset of chronic conditions such as diabetes, hypertension, and heart disease. Exposure to and participation in risk factors in early life may lead to premature limitations in physical activity, psychological illnesses such as depression, chronic alcoholism, and debilitating respiratory diseases.

Contextualizing the risk factors provides a further framework for understanding why people come to be exposed to disease. By contextualizing risk

factors, researchers are able to investigate social circumstances and factors that influence morbidity and mortality, as opposed to exploring only those that are individually based (Link & Phelan, 1995). A contextual understanding towards eliminating health disparities recognizes the relationship between the phenomenon and sociopolitical and economic factors such as income, education, access to care, political power, and human rights, as contributing entities that perpetuate health disparities among vulnerable groups (Allen, 2000). Eliciting health professionals who speak the language of the people they are serving; recognizing, accepting, and incorporating cultural practices into the plan of care, and providing social support to the isolated, are cost-effective strategies that may reduce some of the risk factors associated with health disparities among low-income older adults.

Community attributes such as female-headed households, fewer resources in rural areas, and chronic unemployment are equally important to consider as societal conditions that may affect the health status of a person later in life. The causal pathways producing morbidity and mortality differences in health status are not clearly understood; however, sub-groups of older adults with lower SES generally experience poorer health. Poverty alone may be the primary underlying cause for these disparities. Research has yet to clarify the influence that socioeconomic position has on health status throughout the life span (Robert & House, 2000).

It is also important to consider that there may be a two-way relationship between health and SES; that being, poor health at an early age may have a lifetime negative affect on SES by reducing a person's capacity to work and earn income. Conversely, low income may lead to chronic illness and premature death. People

lacking the social and economic benefits of a steady income in early life, may be burdened with the onset of chronic illness and disability at an earlier age in later life (Robert & House, 2000).

As illustrated in the studies reviewed, the advantage of using quantitative approaches to study the nature of human phenomenon is its ability to measure the responses of a large number of people to a limited set of questions. This approach facilitates comparison and statistical aggregation of the data. Quantitative methodologies provide a broad, generalizable set of findings reflected in numbers to summarize the results of the inquiry in a structured and objective manner.

On the other hand, qualitative methods characteristically produce an abundance of detailed information about a smaller number of people and situations. This increases insight and understanding of the phenomenon studied, but reduces generalizability (Patton, 1990a). Qualitative methods allow the researcher to explore issues of interest in depth, openness, and detail as opposed to being constrained by predetermined categories of analysis such as when using quantitative methods. In qualitative methodology, *“the researcher is the instrument”* (Patton, 1990a, p. 14). The focus of the phenomenological approach is to explore the structure and essence of a particular experience through in-depth interview and detailed description. Husserl (1969) held that we can only know what we experience and “natural knowledge begins with experience (*Erfahrung*) and remains *within* experience” (p. 45).

Preliminary Pilot Project

My interest in health disparities among low-income older adults living in the community resulted in an unpublished preliminary pilot project conducted in Spring,

2003. The purpose of the project was to begin to explore the phenomenon of health disparities from the perspective of healthcare providers who were currently working in a primary care senior health clinic. Specifically the aims of the project were to identify: (a) a typical client seen in the clinic, (b) the special needs of the clients, (c) barriers to care, and (d) the future of healthcare for this population.

Three informants participated in the project: a geriatric nurse practitioner, a medical social worker, and a nurse manager. All worked in the senior health clinic, which was located in a large metropolitan city in Southern California. The participants served clients aged 60 years and older. All clients had Medicare as their primary health insurance and the majority had Medicaid as a supplement. Data collection was accomplished via semi-structured interviews over approximately 60 minutes and note taking. A second interview was conducted for clarification and validation of the information as needed. A brief description of the findings of the project is presented.

Findings of the Project

The informants described a typical client as being elderly, disheveled, cognitively impaired (due to drugs, alcohol, or age), having chronic illness (mental and/or physical), lacking patience, and lacking a sense of time. Predominant diagnoses were diabetes, chronic obstructive pulmonary disease (COPD), and mental illness. Many had complex health issues due to multiple co-morbidities. Barriers to care were categorized as being individual barriers versus system barriers.

System barriers were described as problematic as they interfered with the ability to provide necessary services. Identified barriers were inability to access medical care, lack of healthcare coverage and funding flexibility, rationing of health

services, poor proximity to other health facilities for diagnostic tests and consults, and lack of affordable, appropriate transportation. The shortage of affordable housing and/or near-homelessness was also perceived as obstacles to accessing the healthcare system and as barriers to maintaining proper health.

Individual barriers were also described as ‘internal barriers’ due to a combination of factors such as mental illness and substance abuse. Clients were seen as not ‘valuing’ healthcare or ‘being healthy.’ Clients also ‘lacked tolerance for attention’ given to them by the providers. Internal barriers were manifested by ‘not showing’ for scheduled appointments or refusing preventive screening examines. Other barriers included those that were personal barriers such as poor to non-existent social support, dementia and other cognitive impairments, the lack of education, or the inability to understand healthcare options and benefits.

The future of healthcare for this population was perceived as “bleak.” The current state of the economy, funding cuts in healthcare, and society’s general lack of concern and respect for the elderly put this sub-population of seniors at risk. Funding cuts in Medicare and Medicaid were viewed as the barrier to many providers’ willingness to ‘take on’ the low-income older adult as a client. The development of health promotion interventions specific to the population was expressed as being necessary to prevent illness and disease.

This project had a small sample size, but demonstrated that exploring the human experience was an important source for understanding the complexities of providing care to a vulnerable population group. The results of the project indicated

that much could be learned about a phenomenon when explored through the perspective of those who have lived experience.

Chapter III

Methodology

Phenomenology: this denotes a science, a system of scientific disciplines. But it also and above all denotes a method and an attitude of mind, the specifically philosophical attitude of mind, and the specifically philosophical method (Husserl, 1970b, p. 18-19).

Spiegelberg (1982) describes Edmund Husserl as “the fountainhead and leader of the Phenomenological Movement” (p. 3). He utilized the metaphor *movement* because he viewed phenomenology as a moving philosophy “with a dynamic momentum” (p. 1). This philosophical movement consisted of three phases that occurred primarily during the early part of the 20th century: (a) the Preparatory phase, (b) the German phase, and (c) the French phase. Although Husserl remains the central figure of the Phenomenological Movement, other philosophers contributed to the genesis of phenomenology.

Brentano (1838-1917), the forerunner of the Phenomenological Movement,

and Stumpf (1848-1936), the founder of experimental phenomenology, dominated the Preparatory phase of the movement. Husserl (1857-1938), Scheler (1874-1928), Hartmann (1882-1950), and Heidegger (1889-1976) were the prominent leaders throughout the German phase. The principal figures of the French phase, Marcel (1889-1974), Sartre (1905-1980), and Merleau-Ponty (1908-1961), lead in the development of French phenomenology (Spiegelberg, 1982).

Method

The philosophical underpinnings of phenomenology are multifaceted. Different philosophers offer different interpretations of phenomenology as a philosophy and a method. Common characteristics of phenomenology as a research method are its systematic investigation of phenomenon that is rigorous and critical. But the broad goal of each approach remains unanimous, that is, to gain knowledge about phenomenon. Guided by the philosophical underpinnings of Husserl's ideas about eidetic structures and the Duquesne school approach developed by one of its researchers, Paul F. Colaizzi, eidetic (descriptive) phenomenology was used to elicit the lived experience of access to care among community-dwelling older adults with Medicare and Medicaid (Holloway & Wheeler, 1996; Streubert Speziale & Carpernter, 2003).

As a philosophical discipline, the phenomenological method seeks to understand the events of the human experience under inquiry as lived by the person. Research that yields a rich description of the human experience provides insight about the chosen perspective and how it plays into the way things are (Oiler Boyd & Munhall, 2001). Rather than prematurely leaping into quantifying, comparing, and

correlating aspects of access to care, the research question “*What is the experience of access to care for older adults with government subsidized health insurance?*” was best informed initially through a qualitative methodological approach. The qualitative research question focused on “awarenesses, meanings, and the various ways in which these awarenesses and meanings are given expression as well as their consequences for health and the quality of people’s lives” (Oiler Boyd & Munhall, 2001, p. 618). For that reason, this study’s research question was best answered by using the phenomenological approach.

Husserl’s focus was not on the world as interpreted and created by the scientific approach. Rather, Husserl’s major focus was “*pure phenomena* – independent of and prior to any interpretation, scientific or otherwise” (Valle & King, p. 9). But, there are two philosophical methods that seek to explain the nature of human phenomena. The natural scientific approach (experimental methodology) assumes phenomenon to be observable, measurable, and verifiable by more than one observer. The experiment’s purpose is to test proposed cause-effect relationships by asking “*Why?*” The anticipated outcome is to control, predict, or explain phenomenon. The outward, observable side of human phenomenon is referred to as physical or verbal *behavior* and represents the *objective* aspect of people (Valle & King, 1978).

In contrast however, the phenomenological approach seeks to reveal the structure of experience by asking the question “*What?*” Description replaces the experiment as method, and structure (essence) replaces cause-effect relationships. The researcher seeks to understand the inward, unobservable side of people – the human

condition as evidenced by *real, lived* situations. Thoughts, emotions, and sensations are the private world of the human *experience* and represent the *subjective* aspect of people (Valle & King, 1978). The phenomenologist is allowed the freedom to take on an “understanding-descriptive method”...to “descriptively identify what each phenomenon is” (Colaizzi, 1978, p. 56).

To know what a particular phenomenon is the researcher must begin by contacting the phenomenon as people experience it. Prior to collecting the descriptive data, the researcher must self-interrogate to uncover presuppositions about the phenomenon to determine certain beliefs, attitudes, and theories about it. Presuppositions provide a preliminary basis for formulating research questions. The success of the phenomenological research question is that it gets to the participant’s experience of the phenomenon rather than their theoretical knowledge. The participants’ descriptive responses are then analyzed phenomenologically. In contrast to the experimenter who looks for “*causal explanations*”, the phenomenologist looks to “*identify*” the investigated topic (Colaizzi, 1978, p. 68).

Data Collection

All of the women and men who participated in the study lived in a metropolitan area in Southern California. There are many single-room occupancy (SRO) hotels and subsidized senior apartment buildings located in the downtown section of the city. Prior knowledge and experience informed recruitment of the target population from within this area. Since the goal of the research was to describe the commonalities of the phenomenon, it was important that participants shared particular

demographic characteristics, which represented inclusion criteria for the study participants.

Inclusion criteria. Eligibility criteria for participation included: (a) English speaking, (b) aged 65 or older, (c) living independently in the community, (d) currently receiving Medicare and Medicaid, (e) having known experience with the phenomenon under study, i.e. accessing healthcare services in the community, and (f) having the ability to articulate the experience (Colaizzi, 1978).

Exclusion criteria. Exclusion criteria were: (a) older adults living in assisted-living or board and care facility, (b) diagnosed dementia and other cognitive impairments, and (c) untreated mental illness.

Selection of participants. Thirteen people, 7 women and 6 men, participated in the study. Colaizzi (1978) emphasizes that experience with the topic under inquiry and the ability to articulate is sufficient criteria for participant selection. Research participants were selected utilizing the purposeful sampling approach as it provided some measure of assurance that the selected informants had experience with the phenomenon under inquiry. “Snowball” sampling was also used to identify and locate other participants (Patton, 1990b). Because the phenomenological method seeks to uncover in-depth meaning and experiences, the number of study participants was deliberately small (Baker et al., 1992). However, participants were recruited for interview until no new information was forthcoming and saturation of the data had been reached.

Recruitment procedure. The recruitment process initially involved the distribution and posting of information flyers at a senior health clinic, a senior

community center (SCC), and several senior subsidized apartment complexes (see Appendix A). Two community out-reach nurses and a social worker that worked in the area with the target population agreed to distribute information flyers to interested clients who appeared to fit the eligibility criteria. Other nurse colleagues working in a similar capacity (community clinic, senior center) with the target population were also contacted and provided information regarding the research study.

Prospective participants who called the nurse-researcher to express interest in the project were mailed a packet that included a letter, which further explained the participant's role in the project, a demographic data form (see Appendix B), and a consent form (see Appendix C). Each participant was provided additional information flyers to distribute to friends and neighbors. Telephone number and address were obtained at this time. Two participants did not have a personal telephone and with prior permission, messages were left at the SRO hotel desk as a method of contact. A follow-up call was made several days after the study packet was mailed to determine interest status and schedule an interview place and time.

Upon verbal consent via the telephone, the researcher and participant mutually decided on a date, time, and preferred setting for the interview. A confirmation/reminder telephone call was made the day prior to the interview. At the scheduled interview, the participant and the researcher signed two consent forms. The participant was given one copy of the signed consent and the researcher kept one copy. Some of the participants completed the demographic data form prior to the scheduled interview. For those who did not, the information was obtained on the day of the interview with the researcher reading the form with the participant. Following the

recorded interview, all informants gave verbal permission to be contacted at a later date for further questions and/or data clarification if necessary.

Participants. The 13 participants ranged in age from 65 years to 91 years. All lived alone and in their own apartment except for one male participant who lived with his wife. Some of the participants acknowledged that they were forgetful at times regarding details of dates and times. However, all were cognitively intact enough to meet the eligibility criteria for being able to articulate their experiences with accessing healthcare services in the community. Monthly income ranged from \$774 to \$1,480. Because of income, age, and/or disability, 12 participants qualified for Medicaid with no share of cost. One participant's eligibility fluctuated. See Table A1 *Participant Demographic Data* for a description of the participants obtained from the demographic data form.

The participants were also asked to identify their major health issue, limitations in ADLs, the availability of a care provider when ill, and whether they perceived themselves as having enough money for the provision of basic needs and medicines. Most participants identified some form of limitation in their ability to carry out ADLs and were provided a pre-determined number of In-Home Supportive Services (IHSS) hours to assist with housekeeping, laundry, shopping errands, and such. None of the participants indicated a need for assistance with personal care activities. See Table A2 *Participant Profile (self-identified)* for the descriptions provided by the participants to these questions.

Interview process. As a descriptive qualitative method, phenomenology uses the interview format for data collection. The purpose of the phenomenological

interview in this study was to understand shared meanings by eliciting from the informants a clear representation of the phenomenon under study as lived experience. This included the complete detail and context by which the experience was shaped for each participant. The phenomenological interview combined listening and narratives, thus the interview was not ‘conducted’ but rather ‘participated in’ by both the researcher and the informant (Sorrell & Redmond, 1995, p. 1120).

A self-developed interview guide based on the specific aims of the study was used to direct the interview process (see Appendix D). The informant’s perspectives on access to care and their experiences also “structured” the interview as it took place (May, 1991, p. 191; Sorrell & Redmond, 1995). One face-to-face semi-structured interview was ‘participated in’ with each informant at his or her place of residence or other designated setting of choice. Ten interviews took place in the participant’s apartment/room; two were at the place of residence, but within a room that allowed for privacy; and one took place at the SCC, but also in a private room.

A relationship had been established with some of the participants prior to the day of the interview as a result of several previous telephone calls. These calls provided the participant the opportunity to discuss the study and for the nurse-researcher to begin to get to know the participant. Each interview began with asking the open-ended, descriptive statement: *Describe for me what it is like for you to get healthcare services in your community.* This type of statement and/or questions throughout the interview process allowed the participant to talk about things of importance regarding access to healthcare services and the meanings attached to the experience (Taylor & Bogdan, 1998).

The length of the interviews ranged from 23 minutes to 69 minutes. All participants completed the interview process during the one scheduled meeting. Each participant was given as much time and opportunity to tell their story as they needed and felt comfortable in doing. All interviews were audio-recorded and later transcribed verbatim by a professional transcriptionist. The transcriptionist signed a pledge of confidentiality and the researcher retained a copy (see Appendix E).

Ethical Considerations

The research study was approved by the University of San Diego, Institutional Review Board prior to beginning data collection (see Appendix F). Participants were informed verbally and in writing that their participation in the research study was entirely voluntary and that even after the interview began, they had the right to refuse to answer any question and/or withdraw from the study at any time. Participants were also informed that there might be a risk that they would become tired during the interview process and that they could quit at any time.

Participants were assured that no individual identification would be made at any time during the study or in the final report. Confidentiality and the protection of personal identity were guaranteed by coding each transcript with numbers and letters. Fictitious names were used in the narratives to maintain confidentiality. All data was secured in a locked fireproof safe with access only by the researcher.

The participants were also assured that their participation or nonparticipation or their refusal to answer questions would have no effect on services they received from health or social services providers. A \$25.00 stipend in the form of a check was given to all participants who enrolled in the study. None of the participants withdrew

from the study. The stipend along with a thank you card was mailed to the participant several weeks following the interview.

Data Analysis

A modified version of Colaizzi's (1978) framework for analyzing phenomenological data was used to produce a descriptive analysis of the interviews. Colaizzi's framework was intended to apply to texts such as dialogal interviews or written descriptions by people who have experienced the phenomenon under study. Therefore, this was an appropriate procedure for analyzing the descriptive data generated by the study participants' experiences with accessing care.

The first step of the analysis process began with listening to each recorded interview and simultaneously reading the transcribed manuscript. This step was performed several times to understand the text and to acquire a feeling for the participant's descriptions. Phrases or sentences that directly pertained to experiences of accessing care were then extracted from each description. Colaizzi (1978) refers to this second step as extracting significant statements.

Formulating meanings for significant statements was the third step in analyzing the data. This was the discovery process in which creative insight was necessary to move beyond the transcribed manuscript of what the participants said to understanding the meaning of each significant statement. The transcripts were read repeatedly to illuminate each participant's experiences of accessing healthcare services in their community. In this step the data was allowed to speak for itself. Formulated meanings from all the data were arranged into major theme categories and sub-themes were further extracted.

Within the fourth step, the theme categories and sub-themes were referred back to the original descriptions to validate them with the words of the participants. The emergent themes were thus the commonalities that gave structure to the phenomenon as experienced by the 13 participants. Data findings were integrated into an exhaustive description of the phenomenon and the essential structure of access to care was formulated. The exhaustive description was presented as a narrative account from the perspective of the women and men interviewed.

Trustworthiness (Lincoln & Guba, 1985) was incorporated throughout the analysis process. The transcripts were reviewed line-by-line many times over, in addition to extensive note taking and journaling. This provided the opportunity to ‘dwell’ with the data and reflect on the meaning of access to care as described by the study participants. Intensive engagement with the data (audio-recorded interviews and the verbatim transcripts) and repetition between the descriptions and my interpretation strengthened the credibility of the descriptions. Credibility was also accomplished by sharing transcripts and written analysis with my methods mentor to ensure descriptions were clear and accurate. Recommendations were used to modify the major theme categories and sub-themes, and data interpretation as needed.

A note journal that captured self-reflections and ideas regarding the participants’ descriptions of their experiences was maintained throughout data collection and analysis. Each story was systematically broken down from significant statements, into phrases, and then into simple words. The descriptive data were synthesized into a lengthy narrative about accessing healthcare services.

To maintain integrity and trustworthiness, it was important to examine subjective elements that may be influential to the researcher. The use of reflexivity offered a means of doing this. Reflexivity is defined as “thoughtful, conscious self-awareness” (Finlay, 2002, p. 532). In phenomenological research, bracketing is a form of reflexivity. Bracketing lead this researcher to analyze these data as objectively as humanly possible so that the data could speak for itself.

Chapter IV

Findings of the Inquiry

You know, bureaucracies and governments are very fussy sometimes. And I really think if you want my opinion, the medical care in this country is deteriorating. It's so sad. I think we used to be – I was a flag waver and American gal – boy we're a wonderful country, and I was young when the Japanese attacked us, and we're going to beat them. Well anyhow, things have changed so, and I think it's a sad thing. The fact is you have to be very poor or very rich to get decent care (participant interview, Pat 10/04/04).

This chapter describes the phenomenon of access to care through the lived experiences of the 13 informants who consented to tell their stories for this research study. The experiences are portrayed in each person's unique dialogue to form a descriptive narrative of the phenomenon studied. Although most of the participants expressed gratitude for the healthcare services received, many also spoke about experiences within the system that were frightening, frustrating, and unsatisfactory. The personal narratives of each participant give meaning to what it is like for an older

adult with limited economic resources to access healthcare services in a large metropolitan community.

Five major theme categories and sub-themes were extracted from the interviews that reflect the phenomenon – access to care. The five major themes were: navigating the system, negotiating the system, “it was just too difficult”, “it costs money to be ill”, and “I’m just thankful for everything (see Table 1). To maintain confidentiality, the names in the narrative are fictional, but names are used to uphold the human experience that is absent when a person is labeled with letters and/or numbers.

Table 1. Major Theme Categories and Sub-Themes

Navigating the System

- Ease and convenience
- Finding the resources

Negotiating the System

- Figuring out things myself
- Listening to people talk

“It Was Just too Difficult”

- System obstacles
- Physical disabilities
- Insolent treatment

“It Costs Money to be Ill”

- Limited economic resources
- Funding cuts

“I’m Just Thankful for Everything”

- People make the system work
- System supports

Navigating the System

Being a dually eligible Medicare and MediCal beneficiary was a cherished benefit shared by these older adults. In addition to receiving Medicare, all qualified for the MediCal Program for Aged and Disabled Persons because of being 65 years of age or older. Further, most qualified for MediCal with no share of cost because countable monthly income was at or lower than \$1,028 for an individual or \$1,437 for a married couple (if both apply). Mean monthly income among the participants was \$907.46. The ability to get comprehensive medical care and other health-related services as a result of this eligibility status was considered by many to be a “lifesaver.”

All of the participants had a primary care provider (PCP) and a usual source of care. Most acknowledged having at least one chronic illness such as heart disease, chronic obstructive pulmonary disease (COPD), diabetes, or kidney failure. Illnesses such as these were major health conditions that required on-going medical treatment, specialized medical consultations, prescription medications, and for some the need for costly in-home medical equipment. Utilized health services included medical, psychiatric, and dental; allied health professional services such as medical social services, nutritional consults, and physical therapy; prescription medicines; and durable medical equipment.

Ease and Convenience

For an elderly person living alone on a fixed income and with limited resources, accessing healthcare became an issue of practicability. For that reason, providers who delivered the services directly or those that were easily accessible to the consumer were those most likely to be used. Age and chronic illnesses compounded

failing health and prompted this group of older adults to seek out and utilize healthcare and related services that were easy and convenient. Ease and convenience took on a number of forms and was the result of the desire to remain an independent person living in their own apartment in the community. Age (mean age of participants was 77.3 years), frail health, and physical limitations prompted some participants to use In-Home Supportive Services (IHSS) for housekeeping chores or get home delivered meals. Yet the type and amount of assistance sought also reflected the individual needs of the participant.

According to Jim, the answer for him in accessing the proper health services came about when a senior health clinic opened in his neighborhood. He lived only blocks from the clinic and was so thankful about it being close to his apartment. He said, “I feel like I can just step out the door and talk to a nurse.” In addition to his receiving comprehensive primary care, the clinic also provided him on-going psychiatric services for a bipolar disorder. The clinic nurse filled his medication box weekly, which assured him that he would be taking his medications as prescribed. He told it like this:

So ever since the clinic has been open, they’ve been keeping an eye on the proportions and refilling my prescription needs. Right across the street once a week, I go over and pick them up and they’re all segregated out in daily portions. And I’ve been very satisfied since then.

Prior to the clinic opening, Jim didn’t have a usual source of care and assumed that his aches and pains were a normal part of the aging process. The clinic staff not only provided his healthcare, they acted as his advisors for self-care maintenance by

directing him to other resources as well. This was especially evident when he presented to the clinic with “suicidal inclinations” and was immediately admitted to a facility for treatment. He added, “...when I got the mental health problem...then I became concerned about location of this place, the clinic.” The nearness of the help he received from the clinic staff was reassuring and comforting to him.

Katherine lived in a different building but in the same neighborhood as Jim. Her view of getting care at a senior health clinic was similar to the concept of ‘one-stop shopping’, as all of her medical needs were being met in a single location. Because it was a specialty clinic, she was secure in knowing that her providers would make appropriate referrals based on the needs of an older adult. Specialists and other referrals were coordinated through a multidisciplinary approach and in a comprehensive and personal manner. She considered this beneficial to her maintaining a healthier lifestyle. She explained:

...after the senior healthcare center opened, that was a blessing because all of my needs are taken care of...[it] just involves having all of the referrals and *all* of the services right there where I can be sent to where I need to go....And I have been referred [to] many places and been transported [to] many places under the care of Dr. Y.

Three women identified a physician service that came into their home as their usual source of getting primary care. Each woman told a different story as to how she came about using a physician who made ‘house calls’ for getting her medical needs met. But, each eluded that without this type of service, access to care would be

difficult primarily due to physical limitations, deteriorating health, and transportation difficulties.

Eileen began using the mobile physician service when she developed pneumonia and was too ill to get to her regular physician. She said, “I was just so weak I couldn’t even get up hardly to take care of myself...I was just ready to give up...” She used the words “priceless” and “invaluable” to describe the mobile physician service because it was a service that would come directly to her apartment. For Eileen, access to a service such as the mobile physicians took the form of ease and convenience in being cared for not only when she was ill, but also in maintaining her health. She described it like this:

If I have a need or something, I can call them and they can show up at my door rather than me trying to get out feeling horrible. And I think if I didn’t have the mobile physicians, I just would put aside going to the doctor. Because I just don’t have the means of getting out and being that active, especially with the distance.

Pat’s primary reason for switching to the mobile physician service was transportation. She no longer had a car and it became too complicated for her to make transportation arrangements. Previously, her doctor’s office would coordinate and provide transportation free of charge. But when the office quit providing this service, she found it difficult to get the van to take her at a time when the doctor could see her. She said, “...it was just too hard to get there. I would be ill...and to get on a bus when you’re ill. And the van service just got for me, kind of unsatisfactory.” As a result, she

would supplement visits to her PCP with the mobile physician service when she couldn't get to the doctor's office. She explained:

It's a wonderful service they do offer. But I had to call and then try to coordinate it. It used to be the doctor's office would do it for me and it got so they wouldn't do it. ...they would call and make the arrangements and then put me down, and I'd know I had transportation. Then they got so they wouldn't do that anymore. ...I really did appreciate it. But it got to be where I couldn't get there very easily.

Had the doctor's office continued the service of coordinating her appointments with transportation, Pat would likely have remained with the physician and that particular healthcare system. She was satisfied with her doctor and the care she received. However, the hardship and inconvenience of physically getting to the facility became an obstacle that she could no longer maneuver. Over and over she emphasized that the office "wouldn't do it." The answer for Pat in accessing care that was easy and convenient was the mobile physician service. She added, "And they're very conscientious and very concerned about me."

Kay moved to Southern California shortly after her partner of 30 years died. While caring for him she had not sought treatment for her own medical problems and when she arrived in California she had severe COPD and untreated hypertension. Because of her fragile health, a nurse made arrangements for a physician and other services to be delivered directly to her at her residence. When asked why this type of service was arranged and worked best for her, she said:

Well, I didn't have anything at all when I came. And I could still walk better than I can now...I didn't have my Social Security coming in yet. So she arranged for me to go to the little clinic...so for the first few months I went over there. And then it got harder for me to get around and she suggested instead of walking over there that she'd arrange to have somebody come here.

The shortness of breath (SOB) from the COPD resulted in Kay being very dependent on respiratory treatments that aerosolized a bronchodilator medication. She needed to do a treatment "about every four or five hours around the clock" and would wake in the middle of the night to do one also. Her ability to ambulate any great distance was extremely compromised by her respiratory illness. She could only walk one half block without the need of the bronchodilator. And she only did this a couple times a week. On occasion, she used supplemental oxygen.

The majority of Kay's medical needs were met in her small room in the hotel in which she lived. Her PCP delivered her care here as well as her pulmonary physician. Chest X-rays could be taken and laboratory work performed. A pulmonary service company delivered respiratory equipment and medications directly to the hotel. She didn't have a telephone so her physicians automatically renewed all of her prescriptions that too were delivered by a pharmacy. Although she was restricted by her COPD, she was content to stay in her room and read, or read in the yard occasionally. When asked if she would be able to get to a doctor's office if the doctor didn't come to her she replied:

...Well, if it was that or die, I guess I'd figure out some way to do it. I could always call a cab.... it would be difficult. Yeah, I would have to take a cab and I really can't afford that...

For others, ease and convenience took the form of simply not having any problems with getting healthcare. Joe used the Veterans Administration (VA) Healthcare System for getting his medical needs met and had been doing so for two to three years. He too, had relocated to Southern California after his wife died of cancer. When he initially arrived, he was enrolled in a managed care plan as a MediCal beneficiary. But in talking with a gentleman, he decided to switch to the VA and said, "It's been fine ever since."

Joe was on what he called a "regular schedule" in which he had a standing appointment every six months. His follow-up appointment was automatically scheduled each time he went for a health visit. If a problem arose in-between, he could telephonically access a triage nurse who would direct him to the appropriate level of care. Prescriptions were affordable, \$7 for each and any medical equipment was provided and paid for by the VA. He described his satisfaction with his care like this:

I feel pretty fortunate that the medical thing, the way it is set up now with me personally. I like it. I mean it's good. I feel comfortable. Yes, it's pretty good for a World War II veteran to be able to have that kind of security through VA...after all it's 60 years ago.

Vera too acknowledged not having any problems accessing healthcare. She was well established with her physicians and they were conveniently located to her satisfaction. Appointments were easily attainable and she too had standing health

visits about every three to four months. Follow-up appointments were automatically made each visit. Having MediCal provided a financial savings and for her she said, “...it’s worked out real good.”

Finding the Resources

There were a variety of ways by which finding resources and the right places to go were illustrated by these women and men. Common mechanisms for finding services were staff at the local senior community center (SCC), healthcare providers such as nurses, social workers, and physicians, and the county division of Aging and Independent Services (AIS). In-Home Supportive Services (IHSS) was one of the programs sponsored by AIS and used by more than half of the participants. This program was available to provide homemaker and personal care assistance to persons receiving Supplemental Security Income (SSI) or who have a low income and need aid in the home to remain safe and independent.

Marie, the eldest of the participants, was put in contact with IHSS from a social worker at the SCC. Although asthma and what she referred to as “degenerative spine” restricted her functional ability she was able to live independently in a senior apartment as a result of benefits provided through the MediCal program. She had only been on MediCal for about a year because prior to this time she wasn’t aware that she was an eligible candidate. She explained:

...now that I’m MediCal...it helps me...whatever I need, I can get.... It’s wonderful to have somebody come in and help me, like the girl that comes in on Monday. She does a little cleaning and stuff and does my laundry. It’s a

great help.... I got the oxygen...and I got my breathing machine for my asthma...and I get the medication for the machine too. They bring it to me...

Marie primarily relied on social workers and the nurse at the SCC as her contact for finding resources. Her electric wheelchair (another benefit) kept her from being homebound and provided her the ability and freedom to use the bus system for doctor visits and going for lunch at the local church. Before getting the wheelchair, she was limited in her outside activities, as she couldn't ambulate very far even with her walker. At the age of 91 she was still able to get out and about because of this machine. She said very happily, "...the electric chair is a great help because I can go almost anywhere with it."

The SCC was strategically located in an area that was easily accessible from many senior apartments and SRO hotels. Pat had been using the SCC since it had opened more than 10 years ago. She also had emphysema and wasn't able to walk far because of "gasping for air." It was the nurse from the SCC who referred her to the mobile physician service and who then arranged for her to get a motor scooter so that she could "run around in and do my shopping." She said with a real sense of gratitude in her voice:

...the senior center has helped a lot in enabling me to do many things.... they've been very instrumental in a lot of things...helping me be aware of what I could get and what I was eligible for...I've been in and out of this place a lot for a long time. And they've been very helpful, very helpful.

Others credited this organization with being an invaluable source for finding other resources and services beyond the SCC. Joe applied for VA health benefits

through a veteran's representative that came to the SCC on a weekly basis. Katherine learned about the senior health center opening in her neighborhood from SCC staff. Jean was provided information on getting a mammogram. She referred to the nurse at the SCC as her "guru." She said, "Every time I need something, I run to [RN]. 'Where do I find this? How do I get that?' And she always knows. So she's literally my lifeline..."

Some participants were even more self-reliant in searching for and finding resources and services. When Bill was asked what helped him to get the care he needed he simply said, "I think it's primarily my own research and asking questions of other people, making phone calls, and finding my own way through the system." Bill had been treated for HIV/AIDS for 20 years and was very knowledgeable about his illness. He also realized that his age required him having a provider that monitored age-related conditions such as hypercholesterolemia and hypertension.

After moving to California, Bill went to several different doctors in a one-year period before he found one that was willing to provide him with comprehensive care. He explained:

You can always find an AIDS clinic, but often the doctors just simply want to zero in on that. And at my age, there are other things that need to be looked at as well...I have COPD, I have hepatitis C and you kind of put all that together and I have some medication allergies or medications I can't tolerate. So I've got to have somebody that's going to look at the whole picture and not just the specifics of AIDS.

Bill believed in taking control of his own medical care and tried to do a lot of things on his own. He didn't think a lot of doctors had much experience in caring for elderly people with AIDS. He actively researched medications and treatments on the Internet, took the initiative to question pharmacists about medication interactions, and could even read his laboratory reports. He recognized the role of the physician, but took the point of view that the ultimate decision-maker in his treatment and care was himself.

Bill found it "fairly easy to get access", but believed this to be so because he had AIDS. His perception of accessing care and services as an elderly person was that it would be far more difficult if he only had other medical problems, and not AIDS. He saw this as a "weakness" in the system. He said:

I don't think there's any good system here or a place where you can go as a senior to get the kind of information that you need to get into the right places. I would hate to be in that position. If I didn't have AIDS, I think I'd be having a devil of a time finding the right places to go...There's an AIDS organization...that prints up a pretty comprehensive list of all kinds of services... But I haven't seen anything like that for seniors who don't have AIDS. And I've done a little investigation on my own...

Arthur was a true self-advocate in working the system to get the services he believed he needed. He did not hesitate to call hospital supervisors and department heads to voice his concerns and ask questions. As a MediCal beneficiary, Arthur opted to be enrolled in a managed care plan. However, this required he have a referral from his PCP to see a specialist. When he felt he was being denied access to see a specialist

about skin cancer he wrote a letter to the medical director of the hospital. He got results with a telephone call back and the approval to see the specialist. He explained his approach:

I've had to make phone calls and write people up...Generally speaking, I've had very good doctors and very good nurses, I think primarily because I have stuck with who I've had. ...But, uh, sometimes in life you just simply got to put it in writing and...send it directly to the top dog and let them handle it.

He attributed his ability to communicate with people in steering him to finding the right resources within the system. He related an experience he had when a PSA level indicated he needed further follow-up. He arranged an appointment for a biopsy, which confirmed that he did have cancer. He was then told to make an appointment with an urologist. Yet, when he called to schedule the appointment he was told the urologist was on a month's vacation and there was no one else he could see. It was a scary situation and he had "a very sinking feeling." But he kept talking to the receptionist and she finally offered him an appointment at a different clinic with another urologist. He said with relief:

And I knew I didn't dare let her stop talking, and I kept talking. And it's amazing. I don't care if you're talking about hotel reservations or anything else in life – if you can keep somebody communicating a lot of times you can resolve what the problem is.... But I had known to do that, and a lot of people don't know to do that. That's what's scary. That's real scary.

Negotiating the System

At the age of 65, most Americans can depend on qualifying for the Medicare insurance program for health coverage. Medicaid, on the other hand, is available to those who qualify based on Federal and State government eligibility requirements. Many of the participants were not aware of their eligibility status for the State Medicaid program. Some found out by chance in talking with another person who told them to go apply. Others had the advantage of the assistance of a social worker or nurse to investigate their eligibility status for them.

However, being a dual beneficiary was not all-inclusive for automatically getting the care and services. As a government-administered program, it could be complicated to understand and complex to keep up with the rules and regulations. Each year, Medicare distributes to its participants' new information regarding benefits, rights, and health plan choices. MediCal coverage determinations could also change annually, as well as income eligibility requirements. Occasionally, there was additional legwork by the beneficiary to keep on top of the dynamics of the programs.

Figuring Out Things Myself

Although these men and women credited the assistance of others in getting needed care and services, self-reliance was the most dependable source for negotiating the system. They all had experienced times in which they were challenged in one way or another with such matters as finding a provider who took Medicare, learning about the benefits of their health plan, or where to get information about dialysis. Choices regarding healthcare were made independently as many had no one close to assist

them in the decision-making process. Few spoke of family members or close friends they turned to for advice concerning matters of their health and otherwise.

As a widower and with no family in town, Joe saw managing his healthcare as his responsibility, as well as to stay informed regarding treatment and services. Twenty years working in management taught him to always plan ahead. He continued to use this skill in his approach to ensuring he had adequate health coverage and services. He said:

If something leaves me, I'll look for something to fill that in before I need it. ...I think that a lot of people, if you can't do for yourself to a certain extent, you can't expect somebody else to read your mind...and to plan for you. You have got to do these things yourself! I'm just fortunate I'm able to think ahead to take care of myself to a certain extent.

Others relied on their educational background and their inner strength to persevere in helping them to deal with the complexities of the healthcare system. At the time of the interview, Arthur, who was a retired nurse, was on his fifth managed care plan as a MediCal beneficiary. Because of his income, he had no share-of-cost for Medicare Part A and B, nor did he pay for MediCal. He also had no co-payment for health visits. But again, because of another change with his MediCal managed care plan, he was faced with the possibility of being responsible for partial co-payment for treatment by a specialist. The complexity of the issue prompted him to schedule an appointment with the Health Insurance Counseling and Advocacy Program (HICAP) for advice. In working through the ambiguities of the system, he said:

...in the beginning it was very difficult. But over the years I've learned a lot, and I've had a lot of help, of course. But without my education and my brain of being able to figure out things myself and fill out forms and use the phone very, very well, I wouldn't be where I am today, being fully covered for all my healthcare.

Bill's own determination guided him through the maze of the system. He characterized himself as being "very, very aggressive and persistent in pursuing things." He didn't stop at a "no" or "unacceptable" answer, but continued to pursue until he found the right place. His education and past work experience as a case manager in an AIDS clinic taught him the right questions to ask and how to go about making telephone calls. Even still it was time consuming and not always helpful. He learned to be wary of some information he was given.

I've gotten a lot of misinformation, too, by calling certain places. They'll give me a number to call and then it's the wrong place to call, and they don't know anything about it and they'll give me another number, and I'll try that, and sometimes you go around in circles. And if I weren't aggressive and persistent, it would be real easy to give up, and it would eventually affect my healthcare.

One of Eileen's experiences in figuring out things herself occurred while using IHSS, which she eventually terminated. For her the services were "tentative", unreliable, and "unsatisfactory". In-Home Supportive Services (IHSS) is a federal, state, and locally funded program designed to provide assistance to those eligible aged, blind, and disabled individuals who, without this care would be unable to remain safely in their home. Amazingly though, it is the client's responsibility to locate, hire,

and supervise their own ‘individual provider.’ If services are not performed according to the client’s specification, they also have the right to fire the ‘provider.’

For an aged, blind, or disabled individual, this is an awesome and unrealistic responsibility. For Eileen there was uncertainty as to when the person would show up and what chores the person was willing to do. When this 89 year-old, disabled woman requested her small kitchen floor be mopped, she was told, “that’s not part of the job.” Because IHSS was so unsatisfactory, she terminated the service and family members stepped in to assist. She said:

...I’ve learned a lot too since then as far as dealing with these people who come in to do these services and so forth. Because often times something that’s not valuable to them is very treasured by you and it disappears. They just throw it out in the trash...Not that they are stealing. Of course, I have had stealing too, but that’s another thing...

Eileen hadn’t “bothered” to report the stealing to the social worker or anybody else because she said, “I am so overwhelmed already.”

Charles medical problems were numerous and quite complex, and lead to a long history of interactions with the healthcare system. Adding to the complexities of his health troubles, he was dependent on an electric wheelchair for mobility and had a permanent in-dwelling urinary catheter. He was currently receiving primary care through the VA Healthcare System, but had first-hand experience at a number of other hospitals in the area as a result of emergency room visits and admissions. He described what it was like for him to access care:

Well, it's not that hard really if you go about it the right way...People I talk to, some have pretty good luck and other people don't. The thing is, I tell them what's wrong with me, you know, and what I think. I tell them what the doctors told me and what the nurses told me and it seems to fall in place. Then I hear other people talk about it and they don't ask too many questions of the doctors and nurses and they can't get anything. But with me, I've been pretty lucky.

Although, he felt "pretty lucky" he wasn't always satisfied with the care and services he received. He described his care as being "more group" than individual. Because the VA hospital was a teaching institution, physicians would attend to the patient as a team, but the examination was done in several stages over a period of time. This made for a lengthy visit that was physically and emotionally exhausting. Charles was clearly not pleased with getting his care in this manner. Exasperation in his voice, he explained:

...they come around with doctors; four or five doctors will see you, and then they'll stop to see one patient, and then they'll come over and see you; 'We'll get back to you.' And then they will get back to you late in the afternoon, but by that time you get frustrated cause you wonder what is going on. And by the time they get back, one doctor says, 'What was I here for this morning?' I told him, 'Mark it down, then you'll have it.'

There were times in which the provider would "walk in, they'll do something, and you're out in 20 minutes." This too, was frustrating because he was given no explanation as to what or why the "something" was being done. For example, he

would be given a shot and told to be on his way. When he went to the clinic for a catheter change, they wouldn't talk to him or listen to him about the correct size catheter to use. Unfortunately, when the wrong size was inserted he suffered the consequences by having to go through the procedure again. In the end, he felt events such as these were affecting his health status and outcome.

When Jean was told she had end-stage renal disease (ESRD) and had to go on dialysis she said to her doctor, "What's that?" She talked to people and researched the public library for information but couldn't find anything. She finally called the Kidney Dialysis Foundation who provided her with education literature for the consumer. Jean recognized that it should not have been so difficult to become an informed consumer. She wanted the knowledge about ESRD and dialysis treatment. Life was now very different and centered around her dialysis schedule. Regarding her search she said, "You would not believe what I went through to try to find out something about dialysis... Nobody knew anything. It's a big dark secret." Again, determination was the characteristic that drove Jean to become knowledgeable about her illness.

Listening to People Talk

In addition to established community resources, 'word of mouth' and listening to other people talk were common means for learning about services and other benefits available to seniors living in the community. This served as a way for getting recommendations about providers who took Medicare and MediCal or finding medical specialists. Learning about services close to home was especially useful information to know. The local SCC served as a hub for information gathering not only from the

staff, but also from other seniors who frequented the center on a daily basis. Bus stops and trolley cars were also common places to hear about senior services and benefits.

Joe had stayed away from the VA health system for years. The VA in the city he had lived previously “was very bad”, especially because of the “waiting forever” to get in. He said, “I just stayed away because [of] the reputation.” But several years after being in California and some not-so-good experiences with his managed care plan, a man recommended he try the VA. He transferred all his care to the VA and was very satisfied with his decision. He said that ‘word of mouth’ was his primary resource for finding services and gave a recent example:

For instance, yesterday I was on the trolley and a gentleman had a badge on. It had [city name] on it and I assumed that he was at the...VA home out there and he was. And I asked him questions about the VA, and I don’t want to go out there.

By talking with the man, Joe learned that living expenses were more costly at the VA home and he would have to share a room. These conditions were not appealing to him.

Katherine had been ‘turned on’ to a number of benefits and services through her interactions with other people. Prior to being on MediCal, she was with a senior managed care plan and had “co-payment for everything.” By talking to people she found out about MediCal and the possibility that she might be eligible. She said:

...somebody said, ‘Oh, go down and get some MediCal! You’re eligible.’ And so I did. And thank goodness for that... And the things they have covered have just been amazing when I look at my pile of bills that have been paid. ...it’s been a lifesaver, really.

Finding Medicare providers by talking to people proved successful, but it wasn't necessarily easy. For Katherine, it was "difficult" to get on the phone and try to find a doctor that would take Medicare. She said, "...so many of them just flat out, 'No. We don't take Medicare'." She relied on recommendations from people who said, "Oh, that's good" and "They take Medicare" and "He's real good." She said, "So I follow that lead. And that's not very easy."

In-Home Supportive Services was another service she "found out by listening to people talk." A 'provider' came to her apartment three hours per week to assist with housekeeping. She said, "It's a wonderful service. My place is cleaner now than it would be if it was left up to me." Although this service didn't work for everyone, it was a positive one for her.

She also credited staff at the SCC with giving her health and service related information. It was the SCC nurse that told her about the senior health center opening in her neighborhood. Having her PCP in close proximity to her home "definitely" helped her maintain a healthier lifestyle, as she was more likely to frequent their services on a regular basis since it was easier to access.

Eileen acknowledged her dear friend and neighbor as being instrumental in helping her find different resources and services in the community. It was her friend who called the SCC nurse to assess her when she was so ill. The assessment led to the nurse calling the mobile physician service who had her admitted to the hospital. From this initial referral, she continued to use the mobile physician service more than six years later. She also began to occasionally eat lunch and socialize at the SCC. She said:

[Friend's name] is the one [who] has guided me all along the line. She's been my most valuable friend and true friend, and she is the one who introduced me to [SCC nurse]. I wouldn't have even bothered to go...I would have felt that was an infringement. ...I wasn't even going to go over during lunch. But she said, 'You have to come over for lunch...circulate and get along with people', which is something I was so grateful for too...

She talked about the fun she had with her friends. Occasionally they would get on the trolley and "go scooting around" Old Town in their motor scooters. The benefits this friendship brought to her at this time in her life made her reflect on other women who didn't have what she did. She said:

I just wish some of the women weren't so reluctant to get out...There are women on both sides of me now; they are almost reclusive. ...but when you can't get out, you are fearful. It's really terrible because you can't get exposed to what is available.

She realized that her friend's insistence to get out and about, and make contact with others was a help to her in many ways. She had always been an independent person, but she recognized that as she got older, she was "less able to do...things that I used to do just maybe...a couple of years ago." Because she was less able to handle things, she needed assistance and services that she didn't need when she was younger and more able-bodied. She went on to say:

...I was ignorant of it all and I consider myself an intelligent person. But when you are in a different element and different mode of living completely from what you were used to, it makes a difference, because you are contacting

people and being exposed to other things that you never ever got – another world.

Others agreed that “mostly through word of mouth and friends in the building and neighbors” was a successful way to locate low-cost services and providers. One man learned about the Home Energy Assistance Program (HEAP) while sitting at the bus stop and talking to another man. He also learned about senior services when he worked as a volunteer serving lunch to seniors. He had worked in the health industry and said too, he “had to know myself how to help my patients.”

Another participant found she was eligible for MediCal when she was looking to sign up with a different supplemental insurance provider. She said “a saleslady for a different HMO....put the bug in my ear.” The woman called for her and found that she indeed was eligible for MediCal. This proved to be a tremendous aid, as she no longer had the financial burden of co-payments. Ultimately, working through the system themselves, and listening to each other or those they grew to trust, helped these older adults to negotiate the complexities of the healthcare system.

“It Was Just too Difficult”

The participants discussed a number of barriers that made accessing healthcare services difficult. Inaccessible or expensive transportation, physical disabilities, and other system obstacles were factors that added stress to an already fragile state of well-being. The lack of knowledgeable service providers familiar with senior health issues and other matters important to seniors, were expressed as indirect barriers to accessing services and maintaining a healthy status. Misinformation regarding health insurance

benefits and financial responsibility was especially frustrating. Being treated with disrespect occurred on more than one occasion.

System Obstacles

Transportation in the city was what one participant called “the big bugaboo.” Some of the seniors used an electric wheelchair or motorized scooter to maintain their independence especially when leaving their home. However, these large pieces of equipment sometimes limited use of the public transportation system. One woman said she could get on the trolley, but not on the bus. This restricted her ability to access only those areas of the city that the trolley ran.

For others, long waits at the bus stop and long walks to the doctor’s office after departing the bus were extremely difficult. Metropolitan Transit System (MTS) provided door-to-door service for disabled people who couldn’t maneuver the public transportation system. But MTS could be reserved no more than two days in advance. Taxicabs were expensive, especially when going more than a few miles. And even these modes were not always reliable sources of transportation.

As discussed previously, Pat’s primary reason for switching her PCP to the mobile physician service was the result of difficulty with transportation. The uncertainty of knowing how she would get to the doctor’s office proved to be a burden, especially when she was ill. As a result, she found herself using the mobile physician service when she couldn’t get to her regular doctor. She said:

...I finally just gave up and wrote her a letter. Told her that I thought she was a wonderful doctor, but I was going to have – it was just too difficult to get there

when I needed to see her.... So I finally just gave up, and that's when I had my physician at the mobile physician.

Pat relied on her motorized scooter for getting around to do shopping and errands. Taxis and the MTS were used sparingly as she said, "It runs into a little money." And because her PCP now came to her for both follow-up and sick visits, she only needed transportation services when she saw a specialist.

Charles needed an electric wheelchair for maximum mobility. He had recently spent about six months in a skilled nursing facility because of deteriorating health, but now lived in the community again with the assistance of a caregiver and IHSS. He estimated that he could walk a few blocks on level ground, but would get very fatigued within 15 minutes. Because of his fragile condition, he sometimes needed the medical transport service to take him to his health visits. But travel to the VA for care was becoming difficult. He said, "...it's hard to get somebody to take you now because MediCal doesn't want to pay."

MediCal would pay, but because payment was slow in delivery, some of the transportation companies wouldn't provide him service. Additionally, the physician needed to complete several forms to verify that the doctor indeed saw him. Some of the physicians didn't know how to fill the forms out. He continued:

As long as he fills it out they'll pay it. If you don't fill it out, because I get up there and I miss an appointment and the doctor...is not happy that day...he won't fill it out. Then you're in trouble with MediCal.

Waiting for transportation service to arrive was also difficult. Because of vehicle shortage he occasionally was late for his appointment. He said, "...and if

you're not there by a certain time and then we would have only 10 minutes left. They wouldn't take you, or they're gone..." Charles felt he was "more or less at their mercy" and that "money" was the main concern, not his being on time. If he arrived late and the doctor was still willing to see him, he'd have to wait even longer. Getting a ride home wasn't much easier. He said, "Sometimes they came in half an hour and sometimes they came in three hours. I've waited more than four and a half hours. I could go home on the bus." Getting to and from the doctor was sometimes an exhausting and frustrating venture.

There also was a 'learning curve' in mastering getting on and off the bus in a wheelchair. Until Charles was skilled at 'driving' his wheelchair, he couldn't use the public bus system. He also said it "takes a long time to get them out on the street." Eileen was able to get on the trolley, but not on the bus in her chair. Jean felt some of the bus drivers didn't "like the idea of wheelchairs." Few people in wheelchairs used the bus in her area. Perhaps it was because one particular driver would just keep on going. She said:

...there was one driver who absolutely turned his head to keep going so he doesn't have to pick me up out here...they'll pick up in walkers, but he'll turn his head and pretend he didn't see me, unless there's other people there. Then he has to stop. But like I said, this town does not like seniors.

Others talked about getting a limited amount of transportation vouchers from social services for taxis or MTS. This helped financially, but the service wasn't automatically available when needed. As Arthur put it, "...if you have to go right away or anything in the future, then you've got to either use public transportation, a

taxi, or bus, or walk, or get a freight to take you.” MTS was \$4.50 one way no matter the distance and pick up time for a 9:00 a.m. appointment could be as early as 7:00 a.m. Arthur, who was also wheelchair bound, related how the system worked:

They tell you what time they’re going to be there. And then when you get finished with your appointment, you call, and they give you an approximation of when you’re going to be picked up, and you have to sit there until they come. If the traffic is bad, and it was one time – I’ve sat there and sat there and sat there until I thought I was going to fall out of the chair. ...I just had to keep sitting there.

Arthur told a transportation story which emphasized how a vulnerable, disabled, older person can be ‘at the mercy of others.’ The incident occurred after a visit for physical therapy in which he was waiting outside the building for the van. The office had closed and the staff left not knowing he hadn’t been picked up. He said:

It actually got dark! Everybody is gone! And I thought, ‘What am I going to do? I’m in this wheelchair.’ And I finally found a pay phone, and she said, ‘Oh, I’m so glad you got hold of me. The man is lost and he’s still trying to find you, and he’s out there. Don’t leave! Don’t roll away! He’s coming.’ And I’d been there for longer than two and a half hours. I know that. And finally it got pitch black and dark, and everyone’s gone. If I hadn’t found that pay phone, I don’t know if he would have ever found me. ...You learn the hard way a lot of things in life.

Systems obstacles took other forms such as the PCP serving as the ‘gatekeeper’ to getting an appointment see a specialist, finding a Medicare/MediCal

provider, or being told to call 911 for pain management. Receiving misinformation or inadequate information was also categorized as being an obstacle to accessing appropriate care. Bill's apartment was close to the freeway and the constant exhaust from the cars was affecting his breathing because of his COPD. He wanted to move but was having a difficult time finding affordable housing even after inquiring at several organizations that specifically catered to older adults. He explained:

...I haven't been able to find any place that can provide me with a comprehensive list of housing. So it's a lot of these kind of peripheral services, I think, that are hard to get, are really a part of, let's say, the greater view of healthcare. You know, a lot of healthcare, taking medicine and so on, doesn't do a heck of a lot of good if you're in a situation that is unhealthy.

He had an AIDS case manager, but found her to be "very unfamiliar" and "not trained in senior issues." He was surprised to find that the senior organizations "didn't seem to know very much." He said, "I kept being...referred to one person after another within that organization...I don't know if they're overworked or disinterested...but I wasn't impressed. And frankly, I don't know where to go for that kind of information." He reflected further:

...the issue of accessing medical care is a rather narrow focus in some respects... it's all these other peripheral services that make the difference as to whether or not, even if you have access to healthcare, whether or not it's going to work for you.

Again he recognized that his having AIDS perhaps got him easier access to providers than those who didn't have AIDS. He told of an incident in which he needed to see a specialist:

I noticed some other things about access...I had to go to a gastroenterologist about a year ago...I noticed that he only accepts Medicare and MediCal for people who are HIV infected. So for example, I couldn't go to him if I wasn't HIV infected. And I run into that quite a lot. There are a lot of medical providers that will not take MediCal and Medicare. So you'd have to hunt for doctors or specialists.

Misunderstanding or misinformation of the referral process for getting to a specialist could result in a financial dilemma. This was especially a problem if the MediCal beneficiary was enrolled in a managed care plan. When Joe was in managed care, he went to see a chiropractor and was told by the receptionist that he didn't need authorization from the insurance company. Over a period of time he had four visits for which he was billed \$531. Later, the insurance company told him he did need a referral and authorization, but they wouldn't give it. He told them "there's no way are you getting \$531." He said, "That was the thing that really pushed me, made it firm that I go to VA. ...That's an experience."

Arthur had vision in one eye and the other was a prosthesis. When he got an eye infection, the nurse told him he would still be required to see his PPO physician before he could get a referral for the ophthalmologist. An eye infection for a person with one eye can be serious and frightening. However, there was no flexibility in the

system for him to bypass the PPO physician appointment and go directly to the specialist. He told it like this:

...she said, 'I'm offering you an appointment to see your PPO physician. Do you understand what I'm saying?' What she's implying, if I don't take it, I'm out. I'll have to pay for it myself...I said, 'I understand what you're saying. Of course, get me an appointment with this doctor.'

In the meanwhile, antibiotic eye drops were prescribed while he waited to get his appointments.

According to Charles, the VA system worked in much the same way. Charles acknowledged, "it's been difficult" to get in to see a specialist. He explained the process based on his perspective:

Well, they got to approve it and it has to be approved by that area, that division. And there is a lot of people are really sick; they take them first and leave you behind. So the thing is, you get worse. But if you're really bad, you can get in. Sometimes it's hard for them. You won't die or anything, but the thing is, it takes you a long time to recover, if you do recover.

The healthcare system and providers may also potentiate the inappropriate use of already overburdened emergency rooms (ER). Marie had chronic back pain from osteoporosis. She had Vicodin prescribed, but would only take it at night because it bothered her stomach. When the pain became so severe, she would call her doctor's office only to be told to call 911. Her physician's office would have been more cost-effective and provided a higher quality of care with a shorter wait and delay in treatment. She didn't like calling for an ambulance. But, she was given no choice.

She described what it was like to go to the ER: “Oh! The emergency, oh my God, you spend the whole day there. What did they do? They gave me the Vicodin that I had at home anyway.” Communication between the ER staff and her PCP would have maintained the continuity of care, but this didn’t happen. Instead, she was treated with the same medicine that bothered her stomach and sent home.

Other participants reported accessing the ER for non-emergency healthcare. Arthur had been to the ER three times in a one-year period, twice by calling 911 and once in a cab. None of the visits led to him being admitted. Charles had visited the ER six or seven times in the past year and was admitted for about half of them. One time he was going to be charged because he used 911 and was then sent home. He said, “I wanted to take a cab home. Then I had to sign a release form that I did go on good intention, otherwise I would have had to pay \$500.”

Needing treatment for an acute illness and not getting an appointment with the PCP sometimes resulted in an ER visit, complaints of long waits, and delays in getting care. Vera had severe nosebleeds that required medical attention and several trips to the ER. She said, “Of course when you go there, you got to wait forever. I don’t know why they call it emergency...but they do. And you wait.” Charles was susceptible to urinary tract infections and frequented the ER. He described his visits like this: “They always say I’ll be there for four or five hours, might get sicker, might not get sicker, and usually I do get sicker. You have to sit there and get frustrated sitting around.” Others reported the same. Joe had never used the ER, but his perspective was, “I wouldn’t want to have to go into emergency...as a walking wounded, because I think you’d have to be there forever trying to get care.”

Physical Disabilities

Physical ailments and limitations in functional ability compounded system obstacles in accessing care and services. Although Marie had no problem maneuvering the bus system in her electric wheelchair she acknowledged that without her chair, getting to the doctor would not be easy. She said, “Oh, boy! How would I get there? Use my walker? It would take me hours. I can’t walk very far. No, it would be very difficult, very difficult.”

Kay was nearly homebound as a result of her severe SOB from the COPD. Even though the SCC was less than one block away, she used the home delivered meals service. She said, “...I even got to where walking over there for meals was really hard. I’d huff and puff, and sometimes you have to wait a long time... So that’s was what it [COPD] gets, a little bit worse over time, but I know that.”

Katherine felt fortunate that her current provider was only several blocks from home and offered transportation free of charge. When necessary, she used MTS. She qualified for this service because she couldn’t “see well enough” and “walk well enough” to use public transportation any longer. Getting to her previous provider required she use the bus or trolley system. After departing either one, she said, “I had to walk quite a bit and it was uphill. And a lot of times...it was a terrible effort to get up the hill.”

Katherine didn’t consider difficulty with transportation to be a barrier to her accessing care. She was compliant and did what the doctor told her. She added, “...if the doctor says ‘Go see a doctor,’ I’ll do it. If I have to walk up hill, I’ll walk up hill.” For her, the barrier was that she “didn’t get the overall care.” Her previous PCP was

not a geriatrician and he made few referrals for her. She said, “And thank goodness I wasn’t in very bad shape when I went there.” In the end, Katherine simply wanted a physician who was focused on the special needs of an older adult and could offer her the best care to meet those needs.

Eileen shared a similar story about her previous PCP whom she had for years, but had to get to on the bus. She said, “...that was just too far for me to walk and too far for me to go. At that time I was younger and I was able to get around. ...I had to walk about three blocks from the bus place. I had to walk up a hill and I can remember those.” Moving at a slower pace was a disadvantage. Once Eileen arranged for MTS to take her to an appointment. She said, “...I was just going the last three steps down there [from her apartment]; the man was impatient, and I was ahead of the time and he just took right off.” She consequently had to pay \$20 for a taxi instead of \$4.50 for MTS.

When Bill was diagnosed with hepatitis C, he debated whether or not to do the treatment “knowing that it was going to be very difficult.” Part of his decision and preparation for treatment was finding in-home assistance as he was already having trouble with eating and a very poor appetite. Initially he was told he qualified for IHSS, but further investigation showed a share of cost to him that MediCal would not cover. Although he qualified for MediCal for prescriptions through the state drug assistance program, MediCal wouldn’t be considered for this service. He said:

So all of a sudden they were telling me... ‘Well, first of all you have to be in danger of not being able to remain independent before any services can be given you and be completely homebound.’ And they wanted over \$600 out-of-

pocket expenditure before their services could kick in. Well, it became obvious that...I couldn't do that.

Bill started the hepatitis C treatment, but didn't tolerate it well. The only assistance he qualified for was home-delivered meals through an AIDS organization. Within seven days of starting treatment he became so anemic he was admitted to the hospital for a five-day stay. Upon discharge he had no home health follow-up. He tried the treatment again for six weeks, but ultimately made the decision to quit. There was no other option. He said:

...and then I just stopped. I couldn't do it. Because it partly was that while I wasn't becoming anemic like I did the first round, there simply was no help. And I would have required some help. ...I couldn't afford it out of pocket and I couldn't get the help I needed.

Recovery from an acute illness, in addition to advanced age, chronic illnesses, and being alone, could be fear provoking. After suffering a respiratory arrest, Pat went to a convalescent hospital for pulmonary rehabilitation. Here she was cared for and all her needs were met. She didn't want to leave. She said, "They wanted me out of there because I could walk. I could get around." She learned breathing exercises and how to conserve energy with activity. But she lived alone and was scared to be alone. She said:

I was there just one week at the convalescent hospital and wanted to stay longer...I had never been that ill and I was just a little afraid to come home and be alone, because I was alone. I had nobody to help me. But I came home...It was a frightening experience.

Insolent Treatment

Some participants spoke of experiences in which people within the healthcare system had treated them rudely, with disrespect, and were insensitive to them as a person. One woman told of several incidents in which she felt that she was being discriminated against because she was a senior. Others spoke about not being listened to by their provider or being hurried in and out of an appointment with little time to talk or ask questions.

When Jean went to apply for MediCal she was told by the caseworker that if she didn't have the proper papers to prove what she was claiming regarding income status, she would go to jail. Jean said, "She scared the living daylights out of me." She left without getting the MediCal. The nurse at the SCC tried to convince Jean to return, but she told her, "No. I'm not going back over there. I don't need to be yelled at. I don't need to be told I'm going to jail when I didn't do anything." It was a year before she finally agreed to go back but only if accompanied by a social worker. She concluded:

But that's what you go through mostly when you're a senior. You go to jail if you lie. You're automatically a liar. I don't care if you're carrying a stack of papers you're a liar. ...I feel sorry for anybody that has to go through that.

Prior to being on MediCal, Jean was getting primary care at a community clinic until she "finally gave up." She would wait for hours to get prescriptions filled and felt the staff begrudged the fact that she was even there. She described being treated in a "snappish" manner. But once she had her Medicare and MediCal she was advised to find any doctor she wanted. She did her own research and found a diabetic

specialist, whom she said, “don’t discriminate against Medi-Medi at all.” But she still believed society’s view of seniors was negative and disrespectful. She added:

Oh, seniors are nobody. They wish we’d just go away and die. I’m ashamed to say it and I hate to say it, but it’s true. Nobody wants seniors around. You’re Medi/Medi and you’re old, so go away – go die.

Arthur told of several incidents that involved the co-payment for an office visit and his being treated with disrespect. In one case, the office worker threw his medical record card at him and told him they weren’t going to argue with him about it. Another time, two women at the clinic “ganged up” on him and told him he wouldn’t see the nurse or get his lab work done unless he paid the co-pay. He said, “Luckily I had the money in my wallet; otherwise, I would have had to go out the door.”

In truth, Arthur’s eligibility status did not require a co-payment for office visits. But, ‘the system’ didn’t show his correct status. Because he was new to the MediCal program, he was unfamiliar with how the system worked, and trusted that those who were providing the service did know. After months and many phone calls, he eventually got his money back. Arthur experienced this type of incident on more than one occasion.

Charles had been in and out of the hospital and ER several times for bladder infections. He talked about an experience in the ER when he needed assistance with changing his urinary catheter. His perception as a patient was that of being ignored and that the staff did not want him to bother them. He said:

A lot of the time they don’t come to you. You ring the bell and they shut the buzzer off. You ring it again; they shut it off. And then you got to yell at them

as they are going by. They will turn around and close your door... ‘You are making too much noise.’ ‘I’m here. I’m not going to call you for no reason at all.’...

During this visit he continued to try to get the staff’s attention, but to no avail. “I called... ‘Does anybody work here?’ They just close the door...” Again, he would call, “Open that door. I am not calling for nothing...I got to change these things and I need help.” He could hear the staff outside the door “joking and all that.” He said, “That’s how it’s been for months, for the last five, six months – going down.”

Bill searched for almost a year to find a PCP who would give him the comprehensive care and attention he deserved. After moving to California he went to several physicians before he finally found the right one for him. During his search, he had one doctor whom he said, “...just wouldn’t listen; he didn’t have time. And he’d bury himself in the chart and even though I’d tell him I have something going on he wouldn’t even acknowledge it.” So he switched to another doctor and he said, “It was still 10 minutes. He didn’t pay much attention either...” Eventually, his persistent nature led him to a doctor that would offer him the patient-physician relationship he wanted to have with his provider.

Katherine expressed similar treatment from her previous physician and was grateful for the individualized care she was now receiving at the senior health center. About her previous PCP, she said:

I’d go in and the doctor would talk as fast as he could, shuffle me out many times. It just wasn’t the care, the concern – they didn’t question me, they didn’t

send me out for all these tests. I was just a 15-minute appointment...I was just in and out. So, no, I wouldn't break my neck to get there again.

She too wanted providers that showed genuine concern and interest in her health. Not someone to whom she was "just a dollar sign." Since senior health was the focus of the clinic, she felt staff was more attuned to caring for her needs in a respectful manner.

Pat's experience was somewhat different. Once she was rushed to the hospital ER because of difficult breathing and immediately had a respiratory arrest. The insensitivity of the ER staff during the resuscitation resulted in what she called "a very frightening experience." She could 'hear' what was going on as they intubated her, but nobody was talking and explaining what they were doing to her. She said, "The voices were just like it was magnified." And she didn't know why she couldn't move. She described it like this:

I didn't realize they shoot you so full of tranquilizers you can't move a muscle. None! Not even an eyelid! ...And I'm laying and I hear them talking and everything seems so loud and it's coming right down upon me, and I thought, 'My God! They think I'm dead! How am I going to tell them?' And I worked and I worked trying to move something, and I couldn't move anything, and I was horrified. And I'm scared, got scared. I've never been so scared in my life.

Eventually she calmed down enough to realize they didn't think she was dead since she was still intubated. Finally someone came along and patted her, which provided her with some comfort. She thought, "Well, they do know that I'm alive." After she was extubated, she told the staff:

You should tell somebody, even though you don't know whether they can hear, tell them, 'Look, we know you're in there and it's okay. You can't move anything right now. You'll come out of it.' I was terrified.... it was a very frightening experience.

“It Costs Money to be Ill”

Although material wants and needs may diminish with age, living on a fixed income provided solely from Social Security and for some SSI, was a continual challenge. Dependence on government-subsidized housing, health insurance, nutrition programs, and other services could be cause for worry and frustration. Changes in benefits, State and Federal government funding cuts, and the rising cost of living expenses were factors that couldn't be controlled by any individual. These participants were well aware of their tenuous socioeconomic circumstances.

Limited Economic Resources

Leo was the only participant who was married. He had a monthly income of less than \$800. He qualified for Medicare and MediCal before the age of 65 because of a seizure disorder. Had it not been for government subsidized health insurance, he said, “I would be up a creek without a paddle. ...As far as healthcare is concerned, without that [Medicare and MediCal] I would have to pay out of my own pocket...and with my monthly income I wouldn't be able to.”

Leo had no share of cost for office visits and prescriptions. However, he did take vitamins and the program did not cover these. Shopping at discount stores conserved out of pocket expenses and he was able to get twice the amount at a discount store than he could at a pharmacy. Although the store was far from his home,

he was willing to make the bus trip to save money. Another participant conserved money by never buying anything new. He shopped at thrift stores and ate breakfast and lunch at the senior center. He described himself as being “cagey” in his spending habits to get the most from his limited income.

Eileen also ate at the SCC on occasion, but didn’t like the meals. She was a diabetic and wanted fresh fruit and said, “I do need certain things that I like.” Of all the participants, her income was the lowest. “Everything goes so quickly,” she said. She described herself as being a financially responsible person and prided herself on always being “on top” of her bills. But prior to getting MediCal, she had doubts as to whether she could continue to afford her diabetic medications. Bills were due and she didn’t have the money to pay. She said:

I’ll never forget it. ...I didn’t have \$128 in my bank account. And when they called to nag me about it...I would start to cry over the phone and I’m not a crying person. And I said, ‘Well, I’m just not going to take the medicine anymore.’

For Eileen, this was the worst experience she’d had in trying to get care. She didn’t think she had any option but to go without the medicine. She went on to say:

...I didn’t have enough money to cover it all. ...And when they called me and started nagging me about a \$128 bill, that to me, that was such a shock. I could see the writing on the wall that if this is the way it was going to be, I can’t afford to be sick.

When Jean moved to Southern California she had \$42,000, no insurance, paid cash for everything and “six months later I was broke because of the diabetes.” She

wasn't aware of how to go about collecting her Social Security or finding other benefits she might be eligible to get at low cost or free. But before getting Social Security and MediCal, she used her savings for rent, food and healthcare. For \$25 a month she ate one meal a day in the basement of a church. Initially she thought this would work well financially. However, because of the diabetes and kidney disease she couldn't eat most of the food served. She explained:

I can't eat it because it's got salt; it's got all kinds of things that I can't have.

So it gets expensive when you have to go to restaurants all the time...I couldn't believe it. Money just went! Just disappeared!

Before MediCal, Marie paid for her medications, when she got them, but with her limited income it was "very difficult." She said, "I always owed money. I always borrowed from the bank...and I always had trouble paying the money back and I'd have to borrow again the next month from the bank..." At one point in the conversation she said she didn't take the medicine and "didn't get any medicine." Borrowing from the bank was "standard" for her. With MediCal, her healthcare needs, including prescription medications, were met. Her limited income provided enough money for rent, food and other basic essentials, but not enough to buy clothes.

Although Vera didn't have co-payments with her Medicare and MediCal, getting a medical bill in the mail could be an upsetting experience. She usually didn't get the bills, but on occasion she would receive a bill in the mail. When this happened she would call the service provider right away for the bill to be sent to MediCal. She told about a time she got a bill after being in the hospital with a nosebleed. She said:

They sent me one...it was \$17,000. Ooh, that scared me. And I thought, ‘My goodness sakes, what would I do if I had to pay all these bills?’ Oh, it’s something. ...I would just be one of these street people, I guess, is what I’d be. Vera wasn’t responsible for paying the bill or other bills she might receive. But seeing the written statement for the cost of one visit was frightening. The treatment for her nosebleed was more than her total annual income.

Kay also identified her limited finances as a possible barrier to getting healthcare services. She reminisced on her life with her companion of 30 years and how this affected her present financial situation. They lived on what they made and “had total disregard for buying.” He was a gambler, and as a result they didn’t “build up any money.” Her attitude as a younger woman was “tomorrow is another day.” Now, she only had her Social Security and SSI. She said:

If I had to pay for anything, I’d be dead, yeah. I don’t know what I would have done. I have no idea what I would have done. I didn’t have any money saved.

She took early retirement at the age of 62 and didn’t apply for health insurance because she “didn’t want to give \$65 a month.” She said, “...and at that time when I was 62, ten years ago, you know, I’m going to live forever...” She recognized now that without her subsidized health insurance, “it would be a big financial problem” to get the medical care she needed to stay alive.

The financial complexities of the healthcare system could be overwhelming and certainly confusing to the consumer. When Joe was on Medicare and MediCal his share of cost for MediCal kept fluctuating. For a period he “had zero share of cost” so

he was able to get some dental work done. But two months later, he “was back on 400 some dollars share of cost.” He said:

That was about the time that Sacramento started having all a bunch of problems and they started changing things around. one gentleman’s name was on it and I had a share of cost and then I got something in the mail with a lady’s name on it that said that my share of cost was zero. Then a few months down the line, the share of cost escalated, so I didn’t know what was going on.

Although Joe was now using the VA health system for primary care, he knew in an emergency situation, he would be taken to the nearest medical center, which was not the VA. However, he didn’t have a clear understanding of the process or his financial liability. He tried to find out several times, but was unable to get an answer. He told it like this:

I have never figured out who pays for that...I don’t know if the VA would transfer me out to the VA or leave me there, or who pays for it or whether I have to pay myself or after Medicare pays, or MediCal. ...They got me in there and it’s costing them, somebody has got to pay them. I don’t know if VA would write the check for that. I would probably end up having to pay the cost whatever the cost was.

Not knowing his financial responsibility if he needed emergency care was an unsettled situation. As a consumer who had the right to know, the system failed by not providing him an answer.

Pat was clear that “money mainly” could easily be a factor that would prevent her from getting healthcare services. Her story illustrated the dynamics of the government-subsidized healthcare system. During a period of time she had both SSI and MediCal with no share of cost. But that changed and she then had to pay “40-some-dollars a month to get MediCal.” She was satisfied with her coverage and it was affordable.

Some time later she received a letter that indicated she would no longer have a share of cost for MediCal as she was covered under the Pickle Amendment. Although she couldn’t find out what the Pickle Amendment was, she “was grateful.” Several years later she received another letter, which stated that she would “no longer be on no share of cost” and she would have to pay \$95 a month for MediCal. She called her eligibility worker for an explanation who read her a ‘canned’ statement. She told the worker:

‘Listen, I’m not going to accept that as an answer. I realize you’re told the same answer and I’m not blaming you personally. But, I’m telling you right now I won’t hold still for this.’ I said, ‘This much is ridiculous. ...I’m going to fight this.’

She was given a number to call, which she did “two or three times”. The matter was eventually settled in her favor. She went on to say:

I was willing to pay what I thought was my share. But when they jumped me up to \$95, I was furious...I didn’t ask for the free, I didn’t ask for that. I wasn’t trying to be a freeloader, but I didn’t feel I could afford to pay that.

Pat couldn't remember exactly when she became eligible for MediCal, but could relate it to the time when her husband became ill and she was caring for him. They were able to move into the senior apartment because of his age and he was ill. She said:

You know, it costs money to be ill. And we soon used up what reserve we had. And then he found himself eligible for MediCal because he needed oxygen and everything else. And it was just taking money like mad.

The healthcare system can be rather insensitive to the needs of an ill person and family members who want to care for their loved ones. While caring for her husband, Pat was told she had to go to work. She said, "...my husband was ill by that time. And I said, I'm taking care of him." Someone in the system told her, "We'll pay somebody to come in, but you have to work." She was bewildered by the response she was given and questioned the reasoning. In response she said:

'That really doesn't make sense to me. Why can't I get that pay? I mean, I know what he needs and wants and so on.' But they wouldn't do it that way. We had quiet a time for a while. I had to go out and look for work.

She reflected further:

...you know, bureaucracies and governments are very fussy sometimes. And I really think if you want my opinion, the medical care in this country is deteriorating. It's so sad. I think we used to be – I was a flag waver and American gal – boy we're a wonderful country, and I was young when the Japanese attacked us, and we're going to beat them. Well anyhow, things have changed so, and I think it's a sad thing. The fact is you have to be very poor or very rich to get decent care.

Pat perceived the system as being “kind of unjust” at times. She had a friend who died from a heart ailment and was only covered under MediCal. Pat believed, “had she had money, they would have had a pacemaker in her chest.”

Much of Arthur’s frustrations in accessing care were related to financial situations and what he called “misinformed” people working in the system. Lack of knowledge on the part of the people working in the system sometimes affected his ability to interact with them in an agreeable manner. He voiced his frustration with much emphasis:

Financial situations and people who think that they’re right when they’re wrong! I mean I’m not trying to gyp anybody out of anything. When I own something, I’ll pay it. But if I don’t owe it, I’m not paying it! And I don’t care how long it takes. Now, at one time again, I paid it [co-payment], but I got my money back...and it took me months to get it...

Maintaining benefits that were rightfully his was essential to Arthur. It was so important to him that he viewed it as his “job.” He said, “I look at it as *my* job...I’m not being paid, but in a way I am because I’m saving money.” He believed that if he were not as proactive as he was in looking out after himself “he’d be between a rock and a hard place.” He said, “I might be in the streets or anywhere. I don’t know; it would be sad.”

Funding Cuts

State and Federal funding cuts also had an impact on a person’s ability to get necessary care and services. Charles felt that his experience with the healthcare system in the past year had more of a negative effect than a positive effect on his health. He

believed that if he didn't advocate for himself, "I wouldn't get anything...I would be in bad shape." He saw his 'health going down' and "not getting the proper care" he had been getting a year ago. He said:

They seem to be cutting down all the time. It was going good for a while, but then down it went. They won't spend the money in Washington...to get the services. Oh, I'm getting the services, but not like I got. In other words, they're cutting it short.

As a result, Charles considered leaving the VA health system and going to a private physician. His argument was that he was "not getting the proper care" that he was accustomed to getting at the VA. An additional issue was difficulty with transportation and the hours of waiting. He told himself, "Well, they're not giving me the services I'm supposed to get. I can't get up there and get back properly. It's going to effect me real bad pretty soon, so...I better get out of here."

When Bill was so ill from the hepatitis C treatment, he tried to get in-home assistance. He didn't qualify for assistance through MediCal, and he attributed "cuts in funding" with his inability to get the service as a person with AIDS (PWA). Services such as this were now being limited to only those with AIDS who were most needy. He said:

...most of the services of that sort for people with AIDS has an income cap. I'm just over it. Which doesn't mean a heck of a lot because a lot of people who would be below that income cap have subsidized rents, Section 8, or something like that, and I don't. So they really have more money to spend than I do.

As a PWA, his perception of funding cuts resulted in “a consolidation of services into fewer agencies.” This trickled down to the staff being “more overloaded” and services perhaps not being “as good” as what he had been getting previously. His decision to move to California was also based on Medicaid funding and his ability to access low-cost or no cost services “far easier” than some other states where he had lived. He said, “There are a lot more services here than there are in any of those other places.”

Prior to his move to California, he lived with his mother in Michigan. The application for Michigan’s Medicaid was “just reams and reams and reams of paperwork.” He eventually qualified, but his share of cost was \$900 a month. He said, “When I found that out, I just said, ‘Mom, I can’t stay here. I got to go someplace else.’” In California, his share of cost for MediCal was covered by his state drug assistance program expenditures. He went on to say, “I think Michigan...they want to be rid of you, hope you leave the state.”

“I’m Just Thankful for Everything”

The participants were candid about their experiences with accessing care, even those experiences that were not so good. During the interview, nearly all of the women and men expressed sincere gratitude for being able to get the healthcare services that were currently available to them. Their expressions of gratitude were primarily exemplified through personal encounters with people – physicians, nurses, social workers, community service staff, and other personnel. Positive experiences were related to interactions with providers who were caring and spent time with them

during a medical visit and listened to their concerns; providers who shared information; and staff who showed empathy during times of personal crisis.

People Make the System Work

The study participants fondly recognized healthcare workers who demonstrated a willingness to go ‘above and beyond’ to ensure they were well taken care of. Collective years of accessing healthcare provided the participants with the expertise to evaluate what one woman called “the good, bad, and indifferent.” A positive encounter with people working in the system was the catalyst for making the system work to their benefit.

Jim was “so thankful about the clinic” and the staff who cared for him. As a senior citizen accessing care he was “totally satisfied” with the care he was receiving and believed himself to be “a hell of a lot luckier than most.” He especially attributed his positive attitude to getting the proper care for his mental illness. He said, “...you see, that gives you a little clue about what Dr. S. has done. He has put my mind at ease. He convinced me that I’m really not so bad off.”

Katherine too, was “so thankful” that the clinic opened close to her apartment where she had easy access. She said, “The people there are interested in people.” She believed the staff to be really “interested” in her health and that the care she received kept her “going in as high a gear” as she could “get it in.” To her, there was “a world of difference” and her “healthcare...couldn’t be any better.” Again, she emphasized, “It certainly has kept me going. It’s kept me on the move.”

Katherine also acknowledged the SCC nurse as being “a great help.” She had macular degeneration and was gradually losing her vision. The nurse suggested

applying for a grant as a financial resource to pay for a piece of vision equipment that was not covered by Medicare and MediCal. She said:

...it's wonderful that there are places that you can apply for a grant... You can get them if you have the help. And [nurse] has helped me here. ...I had no idea that there was anything that wonderful out there to help me read. ...I haven't gotten it yet and if I don't, okay, but it's not going to be her fault. She's working hard on it. So that's a good, positively helpful experience.

Eileen too, was especially "grateful" for her relationship with the nurse at the SCC. She characterized her as being a "special person" sent to help those people that were "down on their luck." When Eileen couldn't pay for her medicine, the nurse helped her get MediCal, which was "such a "blessing." The nurse also made the referral for the mobile physician service. She was very appreciative of the physician who came to her home and felt he was attentive to her needs. She credited the nurse and the physician with "saving" her life when she was so ill. She said, "Both of them had come into my life and really protected me."

Pat acknowledged the staff at the SCC with being "instrumental" in guiding her towards benefits and services she may be eligible to access. The nurse assisted her with contacting someone to get a motor scooter so she could do errands. Her doctor agreed with the recommendation and told her, "Well, of course you need something. I don't know how you could shop otherwise." Without the motor scooter, she would be nearly homebound because of the COPD. About the nurse she said, "She's a very concerned and sincere person and she seems to really care what happens to you. So I think that's good."

Pat also talked about the SCC staff that were supportive and helpful during a personal “tragic circumstance.” When she lost her second son, an SCC staff member told her the devastating news. She said, “...I just cried on his shoulder. But without them, I don’t know what I would have done. They offered to help pay for the services. ...They were so good to me.” As a result of their kindness, she entrusted them with making arrangements for her burial service when the time came. She said, “So they will celebrate my life here. And I’m please with that.”

Kay too felt indebted to the nurse at the SCC for helping her to access the services she was receiving. Kay had no knowledge of the services available to seniors and “didn’t have anything at all” when she came to California. She was ignorant of the kind of care she needed to maintain some semblance of quality of life, especially with her severe COPD. She said, “I don’t know what I would have done without [nurse].” She acknowledged the nurse’s “general concern continuing to this day” as being a very positive experience. As a result, Kay was content to live out her “few remaining years” in her hotel room reading or sitting in the yard. She said, “I’m happy.”

Jean had two “very, very good doctors.” When she came to California she was “healthy as a horse.” But within a year she was diagnosed with diabetes and high blood pressure. In time, the progression of both illnesses resulted in kidney failure and end-stage renal disease (ESRD). But, even with three days of dialysis every week, she remained active by providing respite care for the wife of a man with Alzheimer’s disease and reading to an elderly blind woman. Although she wasn’t “thrilled” about the situation she was experiencing, she believed her doctor was doing the “best” he

could “with what he’s got.” She said, “That is the sweetest man. Like I said one time, when he dies I want to be standing right beside him so I’ll go to heaven, too.”

Marie didn’t know she was eligible for MediCal until a social worker helped her with the application process. She no longer had to borrow from the bank and said, “Whatever I need I can get.” In her experience with the healthcare system, “everyone” she had been in contact with “always” helped her. She said, “What would I have done without it [system]? ...when you can’t help yourself in a certain situation and you have somebody to talk to who understands what you’re going through, it was a big help.” When someone understood her and showed compassion towards her when she wasn’t feeling well, it made her “feel great.” She said, “What more can you ask for? It’s just great.”

Bill also rated his experience with the people in the healthcare system as “great.” He was especially satisfied with his physician whom he said “takes 45 minutes with me at least, and sometimes an hour.” If the doctor wasn’t sure of something he wasn’t “afraid to admit” he didn’t have the answer and would consult someone else as necessary. He said,

I like it because he’s listened to me. I’ve just learned over the years...that everybody reacts differently, not only to the virus, but everybody seems to react in a very individual way to the medications. And so it’s necessary for me to be able to communicate with the doctor how I’m being affected, how my body feels.

The doctor’s respectful treatment of Bill made him feel “very confident.” He liked having copies of his lab work, which his physicians were willing to give to him.

The doctor was available to answer questions and would return his calls “right away.” Having previous copies of his labs helped his current doctor determine when he became infected with hepatitis C. He said, “So this is why I keep my labs. And so that’s a good experience, to have them share that information and not be afraid to give it to me.” His experience with nurses was “limited”, but said he found nurses “...likely to be more empathetic with the patient than doctors, and more likely to listen, take a little time, make suggestions.” He added, “Nurses...tend to be broader in their scope and their view, and wanting to know the patient better, and trying to be helpful.”

Arthur complemented several disciplines within the system with helping him get needed care and services. He had a “very good” social worker that worked hard to get him the “peripheral services” such as transportation vouchers and a housekeeper. Office workers and supervisors assisted with providing him telephone numbers and names when he had questions regarding billing and insurance. He was especially grateful to the urologist who did his prostate surgery. He said,

I couldn’t have gotten a better physician...I would have had to been rich and gone to Mayo...he helped me, and gave me things, and talked to me, and gave me free samples, and did all sorts of things! So I was always very thankful to meet Dr....

Although Arthur had several health issues, he managed to maintain a positive attitude and the capacity to be resilient. He acknowledged that his experiences within the healthcare system were “more positive than negative, definitely.” His positive attitude and resilience became very apparent when he told what it was like to be given the diagnosis of having “the big C.” He said:

...I don't care who you are – whether you're a retired nurse or who you are – it scares the hell out of you. So what I did was I got drunk and the next day I dealt with it. And you just get back up and start doing what you know you have to do. And I sure did. But, I think I've been very lucky in life.

Others too, were very pleased with their providers and the care received. Joe said, "...this doctor I've got, he's fantastic." Leo acknowledged the "friendly" staff in the clinic where he received care and that they would "listen" to his concerns. Vera felt her providers kept a "close check" on her and that they were more easily accessible than when she was getting her care through a managed care plan. She said:

...I've been very lucky and very satisfied with everything. I've been thankful, mainly thankful for everything that the county and everything everybody does for me. A lot of people, I don't think, are very thankful for what they get. And I am, very much so.

Vera's expressions of gratitude, however, could very well be the voice of many older adults with limited economic resources who are reliant on subsidized health insurance and other subsidized services to maintain a healthy quality of life. "Finding the best doctors...around and not feeling like I'm begging for help" was what made her experience with the healthcare system positive. She went on to say:

I don't feel inferior to anybody just because I'm on Medicare and MediCal. So I'm just thankful for everything I do have and thankful for the doctors that I have. They are some of the best that are around.

System Supports

The participants also acknowledged their common appreciation for the benefits the healthcare system provided to them as consumers of care. Joe used numerical ranking to score his impression of the system. He said:

On a scale of 1 to 10, I would say right now the whole health situation and the attention that I get...I consider it 10, but I would say a safe 8. Eight would be more than a little less than what I should rate it, but 8 to 10. I don't know of anything that I don't get that I would want.

Joe attributed his perspective to the support he was receiving within the VA Healthcare System. He believed in the people and the system. They were attentive to his needs by ensuring he got the services and care necessary to him maintaining a healthy life. He added, "Whatever the doctor recommends, you get it. ...They're overprotective, I think."

After spending all of her saving, and with much of it going towards healthcare expenses, Jean was pleased with the Medicare and MediCal benefits she was receiving. She described the benefits as "a good deal for us" as the financial burden was now lifted. The services provided to Kay in her home were viewed as a lifesaver. Without them, she said, "I'm not sure I'd be alive. ...I don't think I could make it with my limited income."

Minus Arthur's difficulties with insurance misunderstandings, he acknowledged he "had some good care" and that the city in which he lived had "a lot of benefits for seniors." Transportation services were improving and food programs and housekeeping services were expanding. He lived in a "nice HUD facility" that was

strategically located near the “post office, library, food service, commodities, healthcare, transportation...” In his perspective, the availability of services had improved over the years. He said, “...I’ve seen it improve thank goodness when I needed it. And it has continued to improve, and I hope it continues to.”

Having lived in other areas of the country and experiencing healthcare services elsewhere, Bill was quite satisfied with the services he was currently receiving. He found that it was “far easier here to access services” and that there were indeed more services available to meet his needs. However, he again recognized that perhaps his HIV status attributed to his ability to get more comprehensive services than perhaps others. He said, “In some respects, thank God I’m HIV infected; otherwise, I wouldn’t have the services that I do.”

Without the system supports, Marie and Kay wouldn’t have their breathing machines and supplemental oxygen, and none of the participants would be able to afford their medications. Electric wheelchairs and motorized scooters were all benefits provided by the system to help those in need maintain an independent lifestyle as community-dwelling older adults. Eileen referred to MediCal as having been a “blessing” to her “all the way down the line.” Under the Pickle Amendment, both Jim and Pat qualified for Medicaid. Although Jim didn’t understand what the Pickle Program was, he was grateful it existed and that he was a beneficiary.

Pat described herself as being “very fortunate” to have both Medicare and MediCal and believed had she just had Medicare “would have quite a time” accessing care. As a recipient of both, she had the freedom to choose her providers and

specialists, unlike the restrictions under a managed care plan. She had a final comment about accessing care:

I'm pleased, but displeased with the country and the way most people don't have the satisfactory thing that I do. I think the health setup here in the United States is real crazy. I'm not smart enough to know how to fix it, but I know it needs fixing. It's broken, but not for me. But for the majority of people who are trying to earn a living and they can't afford healthcare, really.

My son was in that state. At one time he was trying to get a business started and driving a truck. And I said, 'You've got no healthcare?' He said, 'I can't afford to pay for it.' The rules and regulations are not good somehow. Something wrong. But for me, I feel very fortunate.

Conclusion

The five themes were common to all of the participants and characterized their experiences of accessing healthcare services in their community. The sub-themes that emerged further illustrated the various perspectives and unique understandings of the phenomenon as described by each participant interviewed.

Overview of Theme Categories

Navigating the system. Each of the participants expressed the importance and value they held in simply being able to receive needed medical care and other health-related services that aided them in maintaining an independent and healthy lifestyle. Consequently, finding the resources and the right places to go throughout the system emerged as a major theme in each of the interviews. Many were constantly met with external challenges even in just finding a provider who took Medicare and MediCal,

finding affordable transportation, finding assistance with housekeeping, and other such services that kept them living in the community. As a result, ease and convenience of service delivery were major criteria to maintaining health and to accessing the appropriate services in a timely manner.

Negotiating the system. Although medical services were available because of having government-subsidized health insurance, services were not necessarily easily accessible. A strong sense of internal resourcefulness was a character trait that emerged among this group. The tenacity to pursue what was viewed as a right, rather than as a matter of charity came forward as the stories were told. These characteristics became apparent as experiences were described that were especially exasperating. Efforts to wade through the ‘red tape’ of the healthcare system were constant and on going. One participant referred to it as his “job” to keep on top of things so as to keep his money in his pocket, his healthcare covered, and to not be destitute. Finding services and the right places to go by listening to other people talk was common practice among the participants.

“It was just too difficult.” System obstacles, such as being misinformed or getting inadequate information, needing a referral to see a specialist, or transportation problems, were some of the obstacles that made it more difficult to get health-related services. Finding accessible and inexpensive transportation to access services proved to be a common problem for many of the participants. For some, fragile health and physical disabilities resulted in dependence on others for assistance in some ADLs and limited their scope of socialization. Stories of discrimination and disrespect were

discussed. And “waiting forever” was not an uncommon occurrence in some healthcare settings.

“It costs money to be ill.” Fixed incomes provided little extra for the ever-increasing cost of living and for healthcare services. The additional benefits obtained through the MediCal program as a supplement to Medicare provided the right to receive comprehensive services without added financial hardship. Although most lived in apartments with a kitchen, the majority depended on senior nutrition programs for meals and commodities. But, access to nutritious food and maintaining a therapeutic diet remained a financial challenge for some. Over-the-counter medications and vitamin supplements were generally an out-of-pocket expense. And some medical equipment or low-vision specialty equipment were not ‘covered expenses’ of the program.

“I’m just thankful for everything.” Many participants described what they perceived to be positive or good experiences they had within the healthcare system in their community. These were exemplified primarily through interactions with healthcare providers – physicians, nurses and/or social workers. Experiences in which providers were caring, supportive, and spent time talking and listening to concerns during a medical visit, who shared information, and showed empathy in time of personal need characterized what were viewed as ‘positively helpful’ experiences. These were also the people who played a supportive role in assisting with getting special equipment and getting referrals to services the seniors may not otherwise get or have known about. Many also expressed their gratitude for the benefits provided by

the system, acknowledging too their luck and good fortune that many others did not have.

The lived experience of accessing healthcare services by older adults with Medicare and Medicaid are multifaceted. As noted in this chapter, commonalities are interwoven throughout the participants' experiences, but still remain personalized to each individual. The major theme categories and their sub-themes depict the *human experience* as evidenced by the participants *real, lived* situations in accessing care in their community. The individual narratives have provided structure to the experience of *what* it is like for an older adult with government subsidized health insurance to access healthcare services. The following chapter presents a discussion of the findings.

Chapter V

Discussion of the Findings

...the issue of accessing medical care is a rather narrow focus in some respects... it's all these other peripheral services that make the difference as to whether or not, even if you have access to healthcare, whether or not it's going to work for you (participant interview, Bill 09/25/04).

This chapter discusses the findings of the research study and explores directions for future research. The study findings were significant in enhancing knowledge for understanding *what* it is like for an older adult to access healthcare services. Access to quality healthcare represents 1 of the 10 Leading Health Indicators of Healthy People 2010, as it is among 1 of the 10 major public health concerns in the United States today (USHHS, 2001c). Healthy People 2010 is about improving the health of all people in the United States. The initiative was designed to achieve two overarching goals: (a) to increase the quality and years of healthy life, and (b) to eliminate health disparities (USHHS, 2001a). Both goals promote increased access to

high-quality healthcare as an opportunity to reduce health disparities and increase life expectancy and quality of life.

Meeting the complex healthcare and social needs of an exploding population of older adults remains a challenge for the United States healthcare system as we move into the 21st century. This population explosion has occurred since over the past 100 years life expectancy for the American person has increased dramatically. In the year 1900, life expectancy at birth was 47.3 years for both sexes and all races. In 2002, average life expectancy at birth was 77.3 years, 30 years beyond those people born at the beginning of the 20th century (Health, United States, 2004). Thus, this study contributed to an enhanced understanding of a contemporary critical health issue.

More than half of the study participants had exceeded the age of normal life expectancy. As one 85-year-old participant stated in regards to long life and her eventual death, “I’m ready, but I’m in no hurry.” But with longevity comes an increase in chronic illness, functional and/or cognitive declines, and for many, limited and inadequate economic resources. All of the participants were affected by these factors and some more severely than others. But these women and men did not dwell on obstacles and limitations, as most were satisfied with their current situations. Nevertheless, obstacles to care existed and challenges within the system were candidly discussed. This study was undertaken to discover the *essence* of access to care by those now experiencing the phenomenon.

Discussion

Access to care, as described by the 13 women and men, was found to have a number of interwoven and interrelated aspects. The participants’ in-depth descriptions

and the utilization of the phenomenological method lead to the discovery of the concepts that gave a common meaning and understanding to the phenomenon of access to care. The structure or *essence* of access to care was the commonalities that were weaved through the many diverse appearances of the phenomenon. The major themes and sub-themes generated by this research were the identified concepts that resulted in a common meaning and understanding of the phenomenon, access to care. This information provides important insight to our understanding of *what* it is like to get healthcare services for those receiving Medicare and Medicaid as viewed through the lenses of 13 older adults' human experiences.

Navigating the System

A classical definition of navigate is “to go from one place to another in a vessel; ... to steer, control, or direct the course of a vessel.” This definition has extended in use as “to direct one’s own course; to make one’s way...(Oxford English Dictionary Online, 2005). The women and men in this study were navigators. They were solely responsible for directing their own course for getting healthcare services and in making their own way through the healthcare system.

Since the inception of Medicare and Medicaid in 1965, access to care matters have been a primary concern of public health and health services researchers. Health insurance coverage, a usual source of care, and the utilization of medical services have been some of the traditional sources used to measure access to healthcare. Other important enabling sources to consider have included the availability of health personnel and facilities, income status, transportation, and waiting times (Andersen, 1995; Cohen, Bloom, Simpson, & Parsons, 1997).

The participants in this study identified all of these sources and more as factors that in some manner either acted as a facilitator or as a barrier to their getting healthcare services. Through personal insight, their stories have brought to life the depth of the complexities that are known to exist within the United States healthcare system. This study also supports what researchers have documented in the literature for many years: that having health insurance and a usual source of care are enabling factors strongly associated with healthcare access and service use (Cohen et al., 1997).

In this study, all of the participants had health insurance, a PCP, and usual source of care. These enabling factors facilitated their use of health services in several ways. For this group of women and men financial access was achieved as dual enrollees of the Medicare and Medicaid programs. Familiarity with their PCP and the ease and convenience of the source of care, enhanced their ability to utilize services to meet their healthcare needs. Those participants who utilized the mobile physician service especially manifested ease and convenience. Not only were medical needs being met, but also identification of safety issues, the need for IHSS, and the need for assistive medical devices could be addressed through the home visit. Reports have shown that home visits can be advantageous to both the patient and the provider particularly with the discovery of unmet healthcare needs (Giovino, 2000; Pozner, 2003; Unwin & Jerant, 1999).

Home care visits are an appropriate response to the needs of an aging population and an increasing number of homebound elderly who desire to remain independent and live in the community. Restrepo, Davitt, and Thompson (2001) reported how a group of geriatric advanced practice nurses (APNs) participated in a

senior house calls program as part of a community out-reach incentive to bring healthcare services to elderly adults who had difficulty accessing care. Their conclusions were similar to those voiced by the participants in this study as reasons for using the mobile physician service. That is, many older adults were unable to access healthcare due to physical limitations, deteriorating health, difficulty in gaining transportation, and lower income. They also concluded that many inappropriately utilized the emergency department for episodic care as a result of their underutilization of primary care services.

The participants in this study that utilized the senior health clinic for care were especially satisfied and confident with the care they received. Continuity of care and a full complement of wellness and preventive healthcare services were offered by the clinic. These are known to be necessary components for providing good, quality primary care. Well-established relationships with the providers and clinic staff also enticed the participants to be regular users of this clinic. As a result they were more willing to readily participate in immunization clinics, preventive screening procedures, medication compliance, and other services that improved or maintained their health and enhanced their quality of life. This senior health clinic is similar in some respects to the PeaceHealth Senior Health and Wellness Center (SHWC) reported by Stock, Reece, and Cesario (2004). The SHWC was also a hospital-based outpatient clinic that focused on the special needs of seniors, especially those with multiple comorbidities and chronic illness.

The local SCC and its interdisciplinary staff proved to be the core resource for finding information about insurance, medical care, and other peripheral services.

Senior community centers (SCC) of this metropolitan area were specifically established to meet the basic human needs of the high-risk urban elderly. Seniors considered to be at risk included those who lived on fixed incomes, most below the poverty level; those in economic or life situations that put them at risk for institutionalization; those in transient or unsafe housing conditions; and those living alone, separated from family and other traditional support systems. In some respect, all of the participants met the criteria of the SCC for being at risk. All had utilized and benefited from the services offered by the SCC and all were extremely grateful for the services rendered.

Probably the most significant unknown benefit among the participants was their eligibility status for the Medicaid program. Many of the participants did not apply for Medicaid or other programs (IHSS) for which they were eligible at an earlier date for a number of reasons. Some did not know about the programs or that they were eligible to apply. One woman was severely intimidated by the documentation process and treated with disrespect. Others simply may have not known where to apply and did not know where or whom to ask. The majority became beneficiaries as the result of someone (usually a nurse or social worker) investigating their eligibility status for them. Nonetheless, this gap in knowledge between the system and the consumer resulted in unnecessary financial burden and emotional stress for some of the participants prior to their enrollment.

In recognition of the complexity and fragmentation of our healthcare system, the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005, was signed into Law on June 29, 2005. The bill (HR 1812) authorizes \$25 million over a

five-year period for grants to “patient navigator” programs that would assist low income, uninsured patients in learning about treatment options, finding clinical trials, and obtaining referrals. It would also alert patients to government aid and help them in applying for financial assistance (Schuler, 2005). The findings of this study validate that these programs should be expanded to include low-income insured patients and closely assessed for resolving patient access issues and in overcoming obstacles to timely diagnosis and treatment of illness and disease.

Negotiating the System

Communication with supportive health providers and word-of-mouth information among friends and neighbors were noted to be essential resources for finding medical care and other services. Although not directly voiced, reliance on one’s own capabilities and judgments was also a revealing characteristic evident among these women and men. Determination proved to be a catalyst for guiding many through the muddled complexities of the healthcare system. Without these characteristics, fragmented care would likely have been their best result.

The participants’ will to maintain a healthy status to the optimal extent possible was also apparent. A healthy body and mind meant being able to live in the community. These participants were well aware of their health conditions and limitations, and some had severe debilitating illnesses. But most were also well aware of the health measures they needed to implement to ensure their remaining independent. These measures included such therapies as breathing treatments every four hours, going to dialysis three times a week, and maintaining an indwelling urinary catheter.

No one spoke of the possibility of transitioning to an assistive living or skilled nursing facility at anytime in the future. All were determined to remain in their current living environment until the end. One participant had even made plans for her building managers to arrange her burial and memorial service. Another participant just wanted to live out her few remaining years in her hotel room and hoped it would not be torn down before she died.

Recent evidence indicates that more people are actively participating in shared healthcare decision making (Tunis, 2005). In addition to healthcare providers, television, magazines, word of mouth, and numerous other external sources are ‘educating’ the American public regarding their healthcare options. Several participants discussed their active involvement in determining their course of treatment for certain illnesses. One participant sought medical care elsewhere because the physician refused to acknowledge his concerns. Another was grateful for the treatment options he was offered after being diagnosed with prostate cancer.

But misinformation, lack of information, an “inappropriate recommendation”, all were identified as obstacles to getting healthcare treatment, health information and other necessary information (i.e. housing and insurance). These obstacles could be frustrating, time consuming, costly, and even life-threatening. Woolf et al. (2005) reported, “consumers encounter a system designed to deliver the material commodities of care (such as tests and drugs) but not knowledge” (p. 293). As a result of such daunting barriers, great efforts must be made on the part of the consumer to get the information about treatment options and self-care management interventions.

Healthcare consumers, including older adults, want, need, and have a right to reliable information to make sound choices. Good information is necessary for making informed choices that maximize health benefits based on the resources available. Several participants described experiences in which they had a difficult time accessing information regarding chronic illnesses that were serious and life threatening. One participant experienced a five-day hospital admission as the result of a provider's "inappropriate recommendation" and failure to act in a timely manner.

Woolf et al. (2005) also indicated that the United States current healthcare system is not designed to "support informed decision making" because of the barriers that obstruct access to information, such as overburdened clinicians. Providers and the healthcare system continue to inform in an obsolete manner. The authors' contend, "patient demand for guidance will only increase as clinical options multiply and the world of information continues its rapid growth" (p. 293). The experiences described by the participants in this study are a testament to this statement.

"It Was Just too Difficult"

Obstacles associated with difficulty in accessing care varied among the group but rendered similar meanings. Words and phrases used to describe their experiences with encountered obstacles ranged from "overworked" and "disinterested" providers to "it's hard," "I just had to keep sitting there," and then, "I finally just gave up." Obstacles resulted in finding other means to obtain the necessary services such as having the physician come to the home instead of going to the physician, word of mouth information among neighbors and friends, and investigating resources independently. But other means were not always available and the consequences could

be feeling as though one was ‘more or less at the mercy of others.’ Lack of interest and response to concerns on the part of the provider was especially viewed in a negative manner.

The physician’s lack of responsiveness to concerns was found by the Cardiovascular Health Study (CHS) to be the most common barrier to affect access to care as reported by Medicare recipients (Fitzpatrick, Powe, Cooper, Ives, & Robbins, 2004). This barrier was reported by almost 33% of the respondents. Other barriers included medical bills, transportation problems, street safety, fear of discovering a serious illness, and fear of unneeded tests. People whose annual income was under \$12,000 were 2.6 times more likely to report a barrier to seeing a physician than those with annual incomes of \$50,000 or more.

The income status of the CHS participants more likely to report a barrier to seeing a physician was similar to the income status of the women and men in this study. Lack of responsiveness and treated in a hurried manner by the physician, were also barriers cited by this study’s participants. One man described a physician he saw as ‘not listening’, ‘didn’t have time’, ‘burying himself in the chart’, and refusing to “acknowledge” his concerns. He decided, “That wasn’t going to work for me” and he found a different doctor. One woman said her previous physician talked as fast as he could and then shuffled her out. She described herself as being “just a 15 minute appointment.” Another woman blamed her internist for her kidneys to “go” because he failed to ‘pay attention’ to her uncontrolled hypertension.

Medical bills (22.3% in the CHS) and transportation problems (21.1% in the CHS) were identified as significant barriers in both studies. However, all of the

participants in this study had supplemental insurance (Medicaid), which eased the burden of medical costs. But, Medicare and Medicaid only provide a basic level of access to the healthcare system. Difficulty in transportation, functional impairments, inadequate income and housing, and discriminatory practices continue to influence equitable access for meeting the healthcare and other basic needs of many people.

Inability to access specialists and other specialty services, such as physical therapy or a chiropractor, was viewed as obstructive to getting what one man called “the proper care.” This was especially so for those participants in managed care organizations (MCO) and the VA Healthcare System in which a referral had to be made by the PCP. Several women chose to not enroll in a MCO because of the lack of freedom to see a specialist at will or the possibility of additional co-payment. The PCP has traditionally been viewed as the ‘gatekeeper’ for controlling the use of these more expensive services, and therefore viewed as restricting rather than facilitating access to specialty care (Grumbach et al., 1999). Grumbach et al. found systems that emphasized the PCP as having this role “undermine patients’ trust and confidence in their primary care physicians” (p. 261), a finding validated in this study.

“It Costs Money to be Ill”

Only five of the study participants definitively answered “Yes” to having enough money to meet the daily needs for acquiring food, clothing, shelter, medicine, and other basic essentials. Their dependence on government-subsidized health insurance was vital to remaining independent since the cost of healthcare has risen significantly over the past 25 years, more so than other costs in the general economy. According to the United States Bureau of Labor Statistics, the consumer price index

for healthcare grew 320 percent, whereas all other consumer prices grew 132 percent (Moon, 2005).

In addition to not being able to afford healthcare, these people were also dependent on other government programs as well. All were reliant on other services such as subsidized housing, nutrition programs, IHSS, and transportation, indicating their severe economic vulnerability. Social Security was never intended to be the single or primary source of income in retirement years. But for the study participants and millions of other older Americans, Social Security, SSI, and veteran's benefits are the economic foundation upon which they live.

The Social Security and Medicare programs were established as a social obligation to the elderly population as a means of providing affordable healthcare and a minimum level of financial security. They were established as on-going programs for all generations to benefit, but are dependent on wage earners financial contributions to remain viable. With inflation overall, and especially in healthcare, these programs are in jeopardy of continuing on as we know them to exist today.

The voices of these 13 women and men captured the reality of the magnitude these programs have on the well being of the older adult population in the United States. This is especially evident among those who experience lower SES, physical disabilities, and chronic illnesses. Two women discussed how their savings "just disappeared" as the result of the high cost of healthcare. Consequently, they became financially dependent on Federal and State assistance programs to provide for their other essential needs.

Two other women discussed the challenges they experienced in trying to pay the high cost of prescription medication, even to the extent of considering or actually not taking the medication. A recent study examined strategies that patients use to cope with high prescription medication costs (Heisler, Wagner, & Piette, 2005). Heisler et al. compared strategies to reduce medication costs such as cutting back on necessities (food and heat), increasing debt, or underusing medication. They found that the use of one or more of these strategies was especially common among patients with low-income, those in poor health, and those taking multiple medications.

However, Heisler et al. (2005) also reported that medication cost pressures was prevalent even among patients with relatively high incomes and/or low monthly out-of-pocket medication expenses. Given this information, special attention should be paid then to those who are most vulnerable and at risk for developing further complications due to their inability to pay for the high cost of prescription medications. Those at risk include the older adult (known to be high users of prescription medications), those that are low-income, and those with serious, chronic medical conditions.

Access to care for low-income and disabled beneficiaries in both the Medicare and Medicaid programs may be threatened in the near future with the steady rise in healthcare costs. With the addition of the Medicare Part D prescription drug benefit effective January 2006, Medicare expenditures are expected to grow significantly. As a result, spending will be cut elsewhere and will likely effect those who are most vulnerable and needy. These developments may include high and rising Medicare cost sharing, limited participation in Medicare Savings Programs, higher payments to

Medicare managed care plans, and proposed reductions in federal Medicaid spending (O'Brien, 2005).

"I'm Just Thankful for Everything"

Although these participants faced numerous challenges in accessing care and maintaining their health, they were not without gratitude for the benefits and support they received. These older adults placed great value on having a clinician and other healthcare professionals see them as people with value, and respect their special needs as an older adult. The desire to maintain autonomy and age in place was supported by physicians, nurses, social workers, and other community service staff. This was manifested by their attentive concerns for issues that went beyond medical care.

The women and men projected a trust in these people who cared for them. This was evidenced by expressions of satisfaction with the majority of the people they encountered in the healthcare system. Those that were especially meaningful were the people who exhibited 'real interest' and were instrumental in securing additional benefits that greatly improved quality of life. A provider that was attentive, that acknowledged concerns, and that viewed the older adult as an active participant in the plan of care was particularly held in high esteem. Spending more time during an office visit, a telephone call, or an impromptu home visit were features that drew special attention to those special clinicians and healthcare professionals.

Critique of the Study

A major strength of this study was the subject itself and the target population chosen for investigation. Access to care is a contemporary topic of concern, not only among older adults, but also among persons of all age groups. However, with the

increase of the size of the population among persons 65 years and older, it was important to focus on this age group since the elderly are more likely to experience functional impairments and chronic illnesses, and have greater healthcare needs.

This study provided an opportunity for low income older adults, a group recognized as being vulnerable and having little or no voice in our society, to share their experiences of accessing healthcare services. The themes and sub-themes developed will add to the paucity of available information about older adults with similar demographic characteristics. The themes and sub-themes also reflect and support some of the barriers described in the literature that can limit access to healthcare, those being financial, structural, and personal barriers.

When little is known about a phenomenon, such as an older adult's experience with accessing care, the phenomenological method can lead to understanding and provide a foundation for future research. The use of this approach allowed the participants to provide descriptive accounts of their subjective experiences of getting healthcare services in their community. In an effort to describe the human experience of access to care as it was lived, this qualitative investigation has given meaning to the phenomenon.

The limitations of the study included its narrow ethnic representation and its focus on one population area in a Southern California city. The researcher found that in-depth, lengthy interviews are physically challenging for older adults, especially those with COPD and other chronic illnesses. This is a consideration that ought to be taken into account when older adults are recruited for participation in research studies.

Directions for Future Research

This research study described the meaning of access to care as perceived by low-income older adults living in the community. Based on the findings, directions for future research are indicated in several areas. The major theme categories and sub-themes necessitate further inquiry and analysis. Further investigation of the themes and sub-themes utilizing quantitative methods may lead to practical, low cost interventions that will facilitate better access to care for this population. The importance of discovering and understanding factors that facilitate access to care or impede access to care is critical to eliminating health disparities known to exist among vulnerable populations in the United States today. Access barriers not only affect persons use of health services, but more importantly persons health outcomes.

The study findings suggest that limited economic resources and their relationship to decision-making for healthcare spending are a critical area for future research. Furthermore, investigation is also needed to identify the decision-making process in relation to healthcare that is used by older adults who have no family members or significant other. Access to this knowledge may be useful in guiding patients regarding costly treatment options or use of expensive prescription drugs.

The data suggest a stronger research focus is needed in investigating factors such as access to medications, health information, transportation, safe and appropriate housing, and nutritious food, and their relationship to increasing the quality and years of healthy life. Public policy specifically addressing these factors could reduce morbidity rate and contain costs, which could further decrease the substantial financial burden for the existing healthcare system.

Health promotion and illness prevention is a primary focus for developing a future program of research. Continuing research in access to care, as a goal to reducing health disparities is a step in the right direction to ensuring good health and fewer illnesses among all population groups. Nurses, physicians, and other health professionals identified as people who make the system work also deserve further investigation in their role as facilitators to healthcare access. Initiatives such as Healthy People 2010 provide a focus point upon which public policy and health researchers can direct future research studies.

Given the strong emphasis on powerlessness and marginalization in these findings, future research efforts could utilize emancipatory paradigms, such as critical social theory, as a lens for further exploration. Research and practice that are grounded in emancipatory inquiry highlight the disparities and injustices that affect individuals' and populations' health in our society. An emancipatory approach into the investigation of access to care and barriers to care among low-income older adults would seek to understand how this sub-population has been oppressed in society. By understanding this phenomenon, that oppression could then be transformed. Emancipatory inquiry recognizes and embraces the influences that sociocultural, political, economic, and environmental risk factors have on scientific research and the need to consciously address these as contributing determinants associated with morbidity and mortality in our society (Henderson, 1995; Northway, 2000).

Conclusion

I will fondly remember the 13 participants who graciously allowed me to enter their home and tell their personal stories regarding this phenomenon. They are the true

pioneers, the ones who have unlocked new ideas and thoughts in this still unsolved phenomenon – access to care. These are the voices of research participants permitted to speak without barriers of precise protocols, instrument tools, and measurement. They shared the truths and realities of their lives from their own perspectives as a contribution towards helping us to better understand access to care.

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Appendix

Table A1. Participant Demographic Data

"Name"	Age	Years of Education	Monthly Income	Source of Income	Health Insurance	Source of Health Care	Primary Care Provider	Dwelling	Number in Household	Mode of Transportation
Jim	79	12	\$847	SS	Medi/Medi	Senior health clinic	Yes	Subsidized senior apt.	One	Bus, Trolley
Katherine	79	14	\$810	SS/SSI	Medi/Medi	Senior health clinic	Yes	Subsidized senior apt.	One	Cab, Van
Bill	65	20	\$1,480	SS	Medi/Medi	Specialty OPC	Yes	Senior apt.	One	Car, Bus, Walk
Eileen	89	14	\$774	SS	Medi/Medi	Mobile physician	Yes	Subsidized senior apt.	One	Bus, Trolley Electric scooter
Pat	85	14	\$853	SS	Medi/Medi	Mobile physician	Yes	Subsidized senior apt.	One	Electric scooter Bus
Arthur	73	16	\$894	SS/SSI	Medi/Medi MCO	Family Practice	Yes	Subsidized senior apt.	One	Walk, Trolley Bus, Cab
Leo	65	12	\$798	SS/SSI	Medi/Medi	Senior health clinic	Yes	Subsidized senior apt.	Two	Bus, Walk
Charles	75	12	\$913	SS	Medi/Medi VA	VA	Yes	Subsidized senior apt.	One	Bus, Trolley Electric scooter
Vera	81	12	\$810	SS/SSI	Medi/Medi	Internist	Yes	Subsidized senior apt.	One	Bus, Taxi
Joe	77	12	\$1,100	SS	Medi/Medi VA	VA	Yes	SRO	One	Bus, Walk
Kay	73	16	\$892	SS/SSI	Medi/Medi	Mobile physician	Yes	SRO	One	Mobile van
Jean	73	12	\$790	SS	Medi/Medi	Internist	Yes	Subsidized senior apt.	One	Electric scooter Bus
Marie	91	9	\$836	SS	Medi/Medi	Internist	Yes	Subsidized senior apt.	One	Electric scooter Bus, Trolley

Social Security (SS); Supplemental Security Income (SSI); Single Room Occupancy (SRO); Veterans Administration (VA); Managed Care Organization (MCO); Medicare/Medicaid (Medi/Medi); Out-patient Clinic (OPC)

Table A2. Participant Profile (self-identified)

"Name"	Major Health Issue	Major Limitation in carrying out activities of daily living (ADL)	Someone to help when sick	Enough money to meet daily needs of food, clothing, shelter, medicines, etc.
Jim	Mental health/bipolar disorder	Difficulty walking due to foot disorder	No	Eats breakfast & lunch at senior center; 'cagey' in spending habits; never buys anything new, shops at Goodwill and Am Vets
Katherine	Macular degeneration; arthritis	Decreased vision from macular degeneration; arthritis	No	Yes
Bill	AIDS, COPD; neuropathy; wasting syndrome; chronic fatigue syndrome; hepatitis C	General fatigue & physical weakness & SOB (affect ability to do normal household activities)	Daughter sometimes	Barely, but it works barring any emergencies; no reserves for emergencies, nor assets
Eileen	CHF; diabetes	Health problems	Daughter-in-law	Living on the "fringe" (financial fringe)
Pat	COPD	When I walk far I need oxygen	Daughter-in-law, friends, senior center	No
Arthur	Obesity	Obesity makes it difficult to do many things	Girlfriend Housekeeper	Yes, but watches budget; home delivered meals; monthly food commodities; eats at senior center
Leo	Heart surgery; partial lobectomy	Asthma	Wife	Yes
Charles	Heart problems; kidney failure; prostate Ca (complications from radiation – incontinence)	Very fatigued within 15 minutes of activity	Housekeeper Friend	Yes
Vera	Heart problems (MI & stroke); implanted pacemaker and defibrillator	SOB; fatigue	Daughter	Yes
Joe	Heart problems; hypercholesterolemia; hypertension	Fine if not exerting to much	No	Generally
Kay	COPD; hypertension	SOB	Yes	Yes
Jean	Diabetes; end stage renal disease (ESRD) renal dialysis 3 days/week	Weakness & inability to walk very far	No	Yes, very carefully
Marie	Osteoporosis; degenerative spine	No identified limitations; IHSS assists with laundry & cleaning	Yes	Not really, enough for food, but not for clothes

Appendix A

Help nurses learn how to better help senior adults with Medicare and Medicaid get healthcare services in their community.

If you are:

- 65 years or older
- Have Medicare and Medicaid
- Live in the community

You are invited to share your personal experience of what it is like for you to get healthcare services in your community.

Your participation will include a 60 to 90 minute audio-recorded interview. You will receive \$25 for your time.

A student nurse-researcher from the University of San Diego is looking for 10 to 12 senior adults to participate in a research project.

If you are interested in participating:

Please contact
Mary Ann Simanello, MSN, RN at
(619) 233-1311

Appendix B

Demographic Data

Gender: Male Female Age Date of Birth

Education (number of school years completed):

Income/month: **Source of income:**

Health insurance:

Usual source of health care:

Primary Care Provider: Yes _____ No _____

Living arrangements (type of dwelling):

Number of people in household:

Method of transportation:

What is your major health issue?

What is your major limitation in carrying out activities of daily living?

Do you have someone to help you when you get sick?

Do you feel you have enough money to meet your daily needs for food, clothing, shelter, medicines, etc?

Appendix C

University of San Diego
Research Participant Consent FormAccess to Care: The Experience of Community-Dwelling Older Adults
Receiving Medicare and Medicaid

Mary Ann Simanello is a doctoral student in nursing at the Hahn School of Nursing and Health Science at the University of San Diego. You are invited to participate in a research study for the purpose of exploring access to healthcare services among older adults living in the community who have Medicare and Medicaid.

The study will involve one interview conducted by Ms. Simanello that asks questions about receiving healthcare in your community. The interview will be about 60 to 90 minutes. A questionnaire asking about your age and other information will take about 15 to 30 minutes.

The interview will be at a time and place convenient for you. Participation is entirely voluntary and you can refuse to answer any question and/or quit at any time. You will receive a \$25.00 stipend or gift certificate for participating in the study, even if you decide to withdraw.

Your interview will be audio-recorded, written, coded, and studied in a manner that protects your identity. A transcriptionist who has signed a pledge of confidentiality will type the interview. Any information provided and/or identifying records will remain confidential and safeguarded in a locked fireproof safe/file for a minimum of five years.

The results of the research study may be made public and information quoted, but all individual data will remain anonymous and confidential. Participation or nonparticipation or refusal to answer questions will have no effect on services that you are entitled to receive from health or social services providers.

There may be a risk that you will become tired during the interview, but you may ask to rest at any time. The benefit to participating will be in knowing that you helped nurses learn how to better help older adults who have Medicare and Medicaid access healthcare services in the community.

You may call the researcher, Mary Ann Simanello, at (619) 233-1311, or her advisor, Dr. Jane Georges at the University of San Diego, at (619) 260-4566, if you have more questions at a later time.

You will receive a copy of this consent form and will be given a chance to ask questions.

I have read and understand this form and consent to the research it describes to me.

Signature of Participant

Date

Name of Participant (Printed)

Signature of Principal Investigator

Date

Appendix D

Interview Guide

1. Describe for me what it is like for you to get healthcare services in your community.
2. Tell me what helped you to get the care you needed.
3. Tell me what kinds of things were barriers or prevented you from getting the care you needed.
4. Tell me how your experience with the healthcare system in your community has effected your health status.
5. Is there anything you would like to add?

Probes

Tell me about a time that things went well when getting healthcare services.

What were the things that made that experience good?

How did that experience make you feel?

Tell me about a time that things didn't go well.

What were the things that made the experience difficult?

How did that experience make you feel?

Appendix E

Transcriber's Pledge of Confidentiality

I will be participating in the dissertation research study entitled:

Access to Care: The Experience of Community-Dwelling Older Adults Receiving
Medicare and Medicaid

I will be transcribing audio-recorded interviews into text. I will not know the names of the informants, but if I should recognize information that enables me to identify any of the participants I agree to maintain their anonymity and confidentiality. By signing this agreement I pledge to keep all information strictly confidential. I will not discuss the information I transcribe with any person for any reason. I understand that to violate this agreement would constitute a serious and unethical infringement on the informant's right to privacy.

Signature of Transcriber

Date

Mary Ann Simanello
Principal Investigator

Date